

Managing Everyday Life: Social Service Use By Mothers
With HIV Infection

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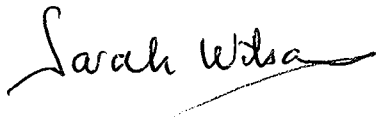
2003



Declaration

I certify that:

- that I am the sole author of this work;
- that this work has not been submitted for any other degree or professional qualification.

A handwritten signature in black ink, appearing to read 'Sarah Wilson', with a long, sweeping underline.

Sarah Wilson

Abstract

This research focused on the service use of HIV-positive mothers. My aim was to explore service use from the perspective of users and potential users of voluntary and statutory social services for people with HIV infection. This approach was prompted by the assumption I thought to underlie much of the literature on HIV services, namely, that once a need had been identified and a relevant service provided, and adequately publicised, it would be used.

I decided to adopt a case study approach focused on Edinburgh. The city, with its relatively high prevalence of HIV infection and density of social services, provided an excellent location for a contextualised exploration of service use. To deepen my knowledge of this context, and prepare for interviews with HIV-positive mothers, I first interviewed ten service providers including funders and representatives of statutory and voluntary, child-centred and adult-focused services.

My concern to explore the social processes, attitudes and experiences underlying the use and non-use of services informed my choice of qualitative methods. The study is primarily based on in-depth, semi-structured interviews with 12 women, who had lived with HIV infection for between seven and 12 years. To reflect the unpredictability of living with a chronic condition interspersed with acute episodes, I decided to interview the respondents twice over the course of some months. Drawing on the high level of intermediate analysis completed between the two interviews, the second interviews were also used to explore recurrent themes raised in the first interviews further, and to map the chronology of each respondent's service use against other important life events.

My findings attest to the importance of exploring chronic illness and service use in the context of wider social, familial and caring relationships, as well as socio-economic circumstances. I focus on the relationship between service use and a continuing process of post-diagnosis identity reconstruction. My analysis of this process relates not only to the diagnosis itself, but explores several other sources of, or influences on, post-diagnosis identity construction, and the inter-relationships

between them. These include motherhood, work, intimate relationships, informal support and participation in service decision-making. The theoretical and policy implications of these findings for the development of services are also addressed.

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Chapter 1: Starting Points

Sitting in my first interview with an HIV-positive mother, I felt a sudden charge of emotion. She was talking about her child in a way that suggested that he should react to her illness in a certain way. Suddenly, I suspected why I had been drawn to undertake a thesis relating to the experience of mothers with a chronic illness. I realised that I might be motivated by my own experience growing up with a parent with another chronic, stigmatised and potentially fatal illness. Perhaps I wanted to see things from my parent's perspective. At the same time, I realised that an important element of this experience for me had been the indifference towards, and, on some occasions, arrogant dismissal, of my other parent by service providers.

In spite of having read numerous criticisms of the positivist emphasis on objectivity in research, I worried whether my PhD project was too 'personal', 'emotional' or even egotistical. I had to admit to myself that at that one moment I had felt a flash of anger at the respondent's expectations of her pre-teenage child, although I had worked hard not to show this. Could I trust myself not to react on another occasion? Would I impose my perception of my years in my parent's home on my analysis, even the conduct of the interviews?

After thinking about this first interview encounter at length, I realised that part of my discomfort related to my own fear of prejudices that children who grow up in difficult environments will always be 'damaged'. In my experience, it is better not to give others the chance to judge. At the same time, I did not feel that I could provide an honest reflection of this project, based as it is on the respondents' generosity, if I did not acknowledge my own experience to some degree. I decided to continue, therefore. I knew that I had learnt very well how not to express my emotions, and to listen. I was also reassured by the fact that the main focus of my interviews was on mothers and their experience of service use, rather than their relationship with their children. I decided I should take each interview as it came, making sure to analyse my own emotions as the interviews progressed.

In the event, this moment in the first interview was the only point at which I felt so uncomfortable, and subsequently I did not often think of my own experience. I found the interviews often moving and sometimes inspiring. The inter-related processes of analysis and writing up, which took place over several years while I was working full-time, produced similar emotions, as well as frustration at the difficulties of working with such rich data.

In the following pages, I have attempted to communicate the process of research and analysis as vividly as possible, emphasising the comments and opinions of the respondents' themselves, but without losing sight of my own role in these encounters.

I present the foundations of the study in my literature review and methods chapters. To report my findings in the following chapters, I have adopted a consistent two-part structure. In the first part of each chapter, or the first of two chapters, I reflect on important themes drawn from my analysis of the data. I then use the second part or chapter to reflect on the findings in relation to the respondents' service use.

Chapter 2: Literature Review

My literature review was the fruit both of previous work as a researcher into legal and ethical issues raised by HIV infection and of more focused preparation for this study.

In the 15 to 20 years since HIV infection and AIDS have been recognised as major problems, a large amount has been written about the epidemic. Prior to 1995, when I started this study, a very large proportion of this literature focused on issues of transmission and prevention [see, for example, Bury, Morrison and McLachlan, eds.: 1992; Bloor: 1995]. Many fewer studies were focused on the care or treatment of HIV-positive people, while the care of HIV-positive women, except as potential child-bearers, received even less attention:

women have been studied primarily in relation to their reproductive role rather than in terms of their own health and wellbeing [Feldman and Crowley: 1997, 123].

By 1995, the lack of focus on HIV-positive women could not be justified and these observations influenced my initial, broad decision to study issues, then unidentified, relating to the care of HIV-positive women. The literature review process allowed me to refine my research aims by identifying gaps, and underlying assumptions in the then nascent literature on HIV care issues.

The literature review therefore constituted a distinct, chronological stepping stone in the development of this study. Since 1995, the literature specifically on care issues for people with HIV infection, but also in other related areas, has developed further. This more recent literature was very helpful in my analysis of the data, and will therefore be interlaced in my discussion of those data. In this chapter, however, I will focus primarily on the literature available to me at the start of this project, and while I was developing the first topic guide between 1995-7. As such, this chapter is not intended as a comprehensive review of the literature in this area, but reflects the literature that shaped my initial research questions.

How Care Issues Were Reflected in the Literature

The literature review reinforced my perception that the existing literature on care issues was dominated by health care, particularly hospital use. Petrou et al., for example, compared the relatively large number of hospital-based studies then in existence with a very short list of studies of social care [1996, 468].

In the mid-1990s, however, a new body of literature on care for HIV-positive people outside hospital, was starting to develop in response to advances in medication, and legal and policy changes. With the introduction of antiretroviral therapies, HIV-positive people were starting to live longer, hospitalisation was no longer seen as the only appropriate care option, and the need for community-based HIV services was belatedly recognised [Rayner and Grimshaw: 1988; Beedham and Wilson-Barnett, 1995, 678]. In part, this development was due to the introduction of the *NHS and Community Care Act (1990)*, which accelerated the shift from institution-based to community-based care [McCann and Wadsworth: 1992; Bornat et al: 1993]. As Petrou et al. point out:

community care for individuals with HIV infection and disease involves many professionals in a wide range of service agencies operating in both the voluntary and statutory health and local authority sectors as well as informal care provided by relatives and friends [1996, 468].

As Layzell and McCarthy's 1992 report on the literature in this area indicated, however, the majority of this work focused on community-based *health* care provision. They identified tensions between medical and social definitions of AIDS care, and between the agencies involved, often resulting from health authorities remaining the lead agencies in service provision [1992, 204]. Atkinson et al. [1996] and Brocklehurst & Butterworth [1996] provided surveys of, respectively, the opinions and experiences of community nurses in Lothian, and home nurses in six English health authorities. Butters et al. [1993, 1995] studied the palliative care work of a community care team through interviews with patients and carers. In Edinburgh itself, Huby et al. [1994, 1995] and Porter et al. [1995] completed a qualitative study

of patients' experience of health care discharge arrangements for HIV-positive people.

The literature review did identify a small but growing UK literature on *social* services. A major focus of this literature was the identification of the needs of different groups of HIV-positive people, primarily by means of questionnaire-type surveys of service users. Perhaps the primary example of this was the Hull-York Research Team study, a wide-ranging, two-year project. One of its main aims was:

to assess the social care and community health care services use (provided formally and informally), unmet demand and service needs of people with HIV infection, ARC or AIDS and an examination of service quality and satisfaction [1993, 6].

Information was collected from service providers across the UK, while questionnaire-based survey interviews were completed with 181 HIV-positive service users in five local authority areas: three in London, Manchester and Lothian (which includes Edinburgh).

Several other survey-based studies attempted to examine the social service needs of different groups of people with HIV: 'by disease stage, gender and transmission category' [Petrou et al.,: 1996, 467], and 'all groups of consumers' [Beedham & Wilson-Barnett: 1995, 678]. Others focused on the needs of particular groups including informal carers [McCann & Wadsworth: 1992], women [Positively Women: 1994; Feldman & Crowley: 1997], and families [Barrett & Victor: 1994]. Other, similar, studies relate to the American context. Mail and Matheny [1989] produced a literature review calling for a greater focus on the social service needs of HIV-positive people at a time when few such services were available; Seals et al. [1995] surveyed 46, mainly African-American, HIV-positive women's opinions of services.

Gaps in the Literature

The literature review process therefore indicated the existence of a developing literature, containing numerous gaps, particularly with respect to social care services. As Green commented:

there has been little research on social aspects of HIV infection [1992, 1].

In the rest of this section, some of the gaps in this literature, which appeared to me to be particularly important, will be examined.

The Lack of Research Focus on Women

My review of HIV literature in general indicated that very few studies had explored women's needs. By the early 1990s, this was a very serious and unjustifiable omission in that the number of HIV-positive women in the UK was increasing rapidly in London and Edinburgh [Bury: 1992b], and astronomically elsewhere in the world [Bury:1992a]. Green's 1992 review of the literature on social support for HIV-positive people is instructive as to the focus of research at the time:

Of the studies listed, the majority have a sample of exclusively homosexual/bisexual men who are, in the main, white and middle class [with the exception of Ostrow et al: 1991]. There are two studies with samples of drug users [Fre et al: 1990, Nabila et al: 1991], and only one each of haemophiliacs [Schneider et al: 1991] and women [Nabila et al: 1991]. Only two studies have a mixed sample in terms of gender and transmission category [Eich: 1990, 1991; Stoll: 1991]. [...] There is thus a strong bias in the current literature toward Caucasian, gay North American males [1992, 13].

Many studies published subsequent to Green's, and even to the start of this study, also had all male samples. For example, all male samples were used in British and American studies of community health care services [see Butters et al.: 1993, 110, and McCormick et al.: 1993, 110], while, in a similar study, Brocklehurst and Butters [1996] provided no gender breakdown of the clients of the nurses they interviewed. McCann and Wadsworth [1992] focused on gay men and their carers. Similarly,

Wight et al. describe their all male interviewees in an American study of the use of social services in the following terms:

These caregivers and PWAs are very similar: most are young, male, non-Hispanic white, gay or bisexual, and well-educated [1995].

An Australian study of the socio-economic living conditions of people with HIV also used an all male sample [Ezzy et al.: 1998].

Other researchers did interview women, although they were usually severely outnumbered by male respondents. In their qualitative study of the experiences of HIV-positive people, for example, Chidwick and Borrill interviewed 20 males and 3 females, none of whom had any children [1996, 274, 278]. Of the Hull-York Research Team sample, 93% were men and 7% women although, in Lothian, the proportion of women respondents increased to 16% [1992, 17-18]. Beedham and Wilson-Barnett [1995] interviewed 69 men and 16 women, while Petrou et al. interviewed 35 women to 197 men [1996, 467].

Whether or not these samples reflected the then gender ratio of people infected in the UK, as contended by Beedham and Wilson-Barnett, the needs of HIV-positive women remained under-explored in these studies. Often, a comprehensive gender analysis of the survey results was not attempted, because of the numbers involved. Chidwick and Borrill did point to one potential difference between women and gay men: the lack of support from a particular community of people with HIV infection [1996, 281]. Meanwhile, other studies suggested, without further elaboration, that the needs of HIV-positive women were met significantly less frequently than those of men [Petrou et al.: 1996, 470].

There were, however, some exceptions. In the United States, Seals et al.'s study confirmed the findings of Piette et al. [1993] that the needs of women were met significantly less often than those of men [1995, 510]. Meanwhile the UK, *Women Like Us* study [1994], based primarily on survey-type interviews with 75 users of Positively Women, a community agency in London, described itself as:

the first piece of community based HIV research into the needs of HIV positive women in the UK [1994, 3].

In another study (published after my project commenced), 27 HIV-positive women and 9 others, either living in close relationships with infected individuals or the bereaved relatives of people with HIV disease, were interviewed using qualitative methods [Feldman and Crowley: 1997, 124]. These studies have contributed, therefore, to a better understanding of the service needs of HIV-positive women.

Having children also seemed likely to make a significant difference to the service use and needs of HIV-positive women. Before I started this project, however, I found only one study of the social and health service needs of families [Barrett and Victor: 1994]. They interviewed 10 parents about their and their child's use of services but did not report on the parents' gender. Another publication collected practitioners' accounts of HIV services available to children and their families in Scotland, focusing primarily on helping children with bereavement [Morton and Johnson, eds.: 1996]. Subsequent studies include Himid et al.: 1998 and New et al.: 1998. Making the valuable point that mother and children's service needs should not be viewed as interchangeable [1998, 195], the latter described their survey as:

a first attempt to describe what services were available to women and children living with HIV in the Greater London area [1998, 194].

The Lack of Empirical Studies Based Outside of London

With a few exceptions [Hull-York Research Team: 1993; Huby et al: 1995], the vast majority of British literature on the provision of HIV services, published before I started this study, was London-focused, including the work focused on HIV-positive women above [Positively Women: 1994; Feldman and Crowley:1997]. Most of the other studies already mentioned in this chapter were all also London-based, and most of their respondents were recruited from teaching hospitals there [McCann and Wadsworth: 1992; Beedham and Wilson-Barnett: 1993, 1995; Barrett and Victor: 1994; Brocklehurst and Butterworth: 1996; Petrou et al.: 1996; Himid et al.: 1998; New et al.: 1998].

The London focus of these studies was potentially significant with respect to certain likely differences in service needs between the populations of HIV-positive women in London and Scotland. Notably, substantially fewer London respondents are likely to have been infected through their own or a partner's injection drug use than in Lothian. In the Positively Women study, less than a quarter of the women interviewed had ever injected drugs [1994, 3]. As discussed below, drug use was potentially significant in deterring mothers from using services.

The huge ethnic mix of London, as compared with predominantly white and English-speaking Scotland, was another potentially significant issue. In the Positively Women and Feldman and Crowley studies, respectively 49% and 71% of their respondents were Black African women [1994, 3; 1997, 124]. Feldman and Crowley warn not to overplay the significance of ethnic or 'cultural' differences in terms of women's needs or use of services [1997, 26]. The emphasis placed in the Positively Women study on the need for translation, immigration and asylum law services [1994, 3-9, 5], however, was less relevant to the Scottish context in 1995, although this is now changing.¹

The Lack of Emphasis on the Socio-Economic Circumstances of HIV-Positive People

The focus of much of the existing literature on gay men may have led to an under-emphasis on the relationship between socio-economic circumstances and service use. Several researchers have emphasised the relatively high levels of education and income among a significant number of gay respondents in the developed world [Wight et al: 1995; Ezzy et al: 1998].

Although some HIV-positive gay men were poor at diagnosis, these articles emphasise the position of those who stopped work post-diagnosis, leading to a loss of income and related benefits [Rayner and Grimshaw: 1988; Beedham and Wilson-Barnett: 1995]. It seems, however, that in general, HIV-positive women have fewer educational qualifications and lower incomes. In the American context, of the 38 women interviewed by Stevens and Tighe-Doerr, only half had completed high

¹ Personal communication with HIV service provider, February 2003.

school and only 2 had jobs: the others relied on social security. The respondents' average annual income was \$7400, while one quarter only received \$4000, and several had experienced homelessness [1997, 524-5; also see McCormick et al: 1993, 372; Seals et al: 1995]. In the Canadian (Ontario) context, Bastow [1994] reported that many social assistance benefits were based on the then AIDS diagnosis, which better reflected AIDS-related conditions in men, excluding many AIDS-related gynaecological conditions affecting women.

The relevance of socio-economic circumstances to HIV-positive women in Scotland was suggested by the Hull-York Research Team's finding that, of the regions they surveyed, Lothian had the highest proportion of women, the lowest proportion of respondents with academic or professional qualifications, and the lowest income levels. About 45% of the Lothian respondents were receiving Income Support only, the least generous UK means-tested benefit [1992, 17-18].

The general significance of socio-economic circumstances, and of the difficulties relating to living on and negotiating with social assistance agencies, were reported in several British studies [Positively Women: 1994; Beedham and Wilson-Barnett: 1995, 681]. Butters et al. emphasised the importance to their very ill respondents of the availability of social security benefits [1993, 107]. Beedham and Wilson-Barnett highlighted the problems encountered by respondents dealing with the Benefits Agency, including poor communication and not returning phone calls and letters [1995, 681].

Similarly, several UK studies emphasised the importance of housing problems [see Firth: 1987; Positively Women: 1994]. Beedham and Wilson-Barnett catalogued numerous housing problems experienced by 40% of their respondents including living in accommodation, sometimes temporary accommodation, inappropriate for sometimes rapidly changing health needs, and the difficulty and delay involved in obtaining housing transfers [1995, 680]. Other problems included respondents' perceptions of insecurity and actual harassment on account of their diagnosis, or sexual orientation [1995, 680-1]. The Hull-York Research Team's Lothian sample reported the highest rates of dissatisfaction with housing, of being without their own accommodation, and of HIV-related harassment [1993, 37-38]. All of these

problems were recognised in subsequent policy guidelines for Scottish Housing providers [Positive Housing: 1995].

By the time I started this project, therefore, several studies had reported on the socio-economic circumstances of HIV-positive people. They did not, however, explore the relevance of such issues to the use of services beyond the social security and housing services themselves. The potential influence of socio-economic circumstances on service use was, however, suggested by my reading of other literature on women, poverty and health [see Blaxter and Paterson: 1982; Cornwell: 1984; Graham: 1984; and Payne: 1991] and I decided that this should be an issue for further exploration in this study.

Research Into Social Service Use

Wight et al highlighted the lack of research focus on actual service use:

Previous research has focused on describing the types of services that have emerged to meet the needs of the AIDS-affected community. There is little research concerning predictors of service utilization. [...]. Additionally there is scant information available concerning unmet need for AIDS services and the barriers to meeting these needs [1995, 509].

Some of the studies already mentioned did examine practical barriers to service use, although this tended to be a secondary focus of analysis [Hull-York Research Team: 1993; Petrou et al.: 1996]. A major exception to the lack of focus on service use did relate to women, however. This was the much discussed concern that mothers, particularly drug users, would be deterred from using HIV-specific services by the fear of social worker intervention.

Practical Barriers to Service Use

The practical barriers to social service use highlighted included the lack of transportation and childcare [Positively Women: 1994, 3; Kissinger et al.: 1995] and transport, time, money and childcare [Barrett & Victor: 1994]. Lack of childcare was also mentioned by Feldman and Crowley [1997, 127].

Several studies found lack of information to be a significant barrier to service use:

[t]he relative lack of association between the PWA's overall health status and service use may indicate that use is more a matter of knowing how to access services than a matter of need [Wight et al.: 1995, 517].

Petrou et al. also raised this concern:

[t]he frequencies of unmet need for many community services were high and often seemed to arise either from a *lack of awareness* on the part of subjects of how and where services could be obtained or from doubts about the relevance of services offered. Both of these barriers should be surmountable through the provision of better information to patients [1996, 467].

Similarly, the Positively Women survey found some women to be unaware of what they might obtain through social services [1994, 2]. Feldman and Crowley suggested that access to information about the health and social care system might be more difficult for women to obtain as they are likely to be more isolated from HIV information networks than gay men [1997, 128, 136]. As such, they suggest that the availability of information about services may be linked to the availability of informal support. Informal support in itself was also the primary focus of Wight et al.'s study of service use in which it was suggested that a caregiver's need for respite might make service use more likely [1995, 516-7].

Few of these studies problematised the services themselves. One exception to this was the suggestion that facilities, often designed for and by gay men, were inappropriate for HIV-positive women and their families. Beedham and Wilson-Barnett, for example, found that gay men were more likely to use the services they surveyed than any other group, and that others, particularly mothers with young children and heterosexual men, often complained that these services were 'cliquey' [1995, 685].

The Fear Of Children Being Removed

As indicated, however, much of the literature on HIV-positive mothers' service use that I read prior to starting this study focused on the well-founded fear that, should they use services, their children might be removed.

Legal and other sources provided many indications of why HIV-positive mothers, particularly drug users, might be deterred from using services. As mentioned, much of the early media interest in [see Reeve: 1996, 16], and literature on HIV-positive women, including in Scotland, was dominated by the concern to prevent transmission, particularly vertical transmission. This concern was reflected in a large number of studies, in many countries, aimed at estimating the prevalence of HIV infection in pregnant women [Sherr: 1993, 47]. This suggests that vertical transmission was perceived as more significant than the effects of HIV infection on mothers themselves [see Barbacci et al.: 1989; Cohen et al.: 1989; Johnston et al.: 1989; Sunderland et al.: 1989; Wiznia et al.: 1989; Selwyn et al.: 1990]. As Squire comments:

[p]regnant women [...] [are] the focus of intense social concern about the economic and social costs of HIV sero-positive babies [1993, 17].

Hostility towards drug-using and HIV-positive mothers has been particularly pronounced in American policy, legislation and jurisprudence. For example, the Centers for Disease Control (CDC) and the United States Public Health Service recommended that HIV-positive women should be advised to consider delaying pregnancy until more was known about perinatal transmission of the virus [Morbidity and Mortality Weekly Report: 1985, 725; Francis and Chin: 1987, 1361]. This recommendation was made in spite of the prevailing concern that counselling should be non-directive for women at risk of passing on genetic disorders to their children [Bayer: 1990, 182, 193-5]. A recommendation that HIV-positive women should be advised to have terminations was deleted as too politically sensitive [Amaro: 1993, 26-7].

In several American jurisdictions, criminal offences of supplying drugs were applied to women who use drugs during pregnancy [Johnsen: 1986; Moss: 1990; Roberts:

1990; Robin-Vergeer: 1990],² while some states introduced legislation making the vertical transmission of HIV infection a criminal offence [Sprintz: 1993]. Courts in some jurisdictions were also willing to interpret child protection statutes to include the foetus,³ while several, including Illinois, amended statutes to this effect [Moss: 1990, 292-3].

These developments received wide publicity in Britain, where child protection statutes have also been interpreted in such a way as to justify the removal of a child from mothers who use drugs during pregnancy. In *D (a minor) v. Berkshire County Council and others* [1987] 1 All ER 20 [*D (a minor)*], the House of Lords in effect applied a presumption that drug-using mothers were necessarily unfit. Dillon LJ, in the Court of Appeal, stated:

I would stress that there is no question whatever in this case of giving the child back to a mother who is a drug addict [at 32].

While it is clear that chaotic drug use often does raise child protection concerns [McKeganey et al.: 2002], the fact that this decision was made in the absence of any evidence as to the actual parenting abilities of the parents involved suggests a punitive approach.

While *D (a minor)* was an English case, legal commentators had little doubt that a similar approach would have been taken by the Scottish courts [Dewar: 1989, 286; Thomson: 1991, 234, 243]. Further, although the legislation⁴ under which this decision was made has since been superseded, it is important to note, that many HIV-positive Edinburgh women were diagnosed, and some were using drugs, at the time this case was decided.

At this time, several writers noted that women used community drugs services less than men. Commenting on reports that Scottish drug projects are patronised 2:1 by

² See *State v. Johnson*, No. E89-890-C.F.A., slip. op. at 1 (Fla. Cir. Ct. July 13 1989) affirmed No. 89-1765, 1991 Fla. App. LEXIS 3583 (Fla. Dist. Ct. App. April 18 1991); *In re Stefanel Tyesha C.* 157 App. Div. 2d. 322 (1990); *In re Baby X* 97 Mich. App. 111, 293 N.W. 2d. 736 (1980); *In re Valerie D.* 595 A. 2d. 922 (Conn. App. 1991).

³ See *Matter of Smith* 492 N.Y.S. 2d. 331 (Fam. Ct. 1985); *In re Stefanel Tyesha C.* 157 App. Div. 2d. 322 (1990).

⁴ *Children and Young Persons Act, 1969*, c.54, ss.1(2)(a), 28(1).

male clients, Morrison suggested that women fear being seen as not coping and that they will be considered unfit mothers [1992, 46-7; also see Henderson: 1994, 185-187]. An Edinburgh service provider commented that:

a woman may feel intense guilt over not achieving the socially acceptable standard of mothering but she may also be very afraid that if she discusses her drug use or that of her partner, her children may be placed on a supervision order or be taken away from her [Wilson: 1992, 112].

This fear was also discussed in the social work literature:

[m]any women drug users associate social workers with their role of receiving children into care. Indeed many stigmatised families may well have experienced services as judgmental, punitive and unsympathetic. Barriers of distrust and alienation must be broken down in order to convince families that services are open, non-judgemental and accessible [Powell, 1992, 25; also see McCrae: 1989, 11-12].

Social workers' difficulties in dealing with parents who use drugs were acknowledged in a 1996 article in a publication widely read by practising social workers. Rickford reported on research indicating no causal link between drug use and child abuse or neglect, and emphasised that the adequacy of each family's parenting should be assessed individually against the usual child protection criteria [1996, 20].

In many cases, however:

[i]gnorance [of drugs] among child care social workers, and self doubt in assessing risks, are prime problems

and she suggested that this may lead them to panic [1996, 20].

While drug-users may have been most likely to have been deterred from services provided by the Social Work Department [SWD], other sources suggest widespread unsympathetic attitudes among service providers towards all HIV-positive mothers at the time. A solicitor's contribution to a 1987 British Association of Adoption and Fostering [BAAF] publication on the implications of HIV infection suggested that *D*

(*a minor*) be used to take into care the children of HIV-positive women who were infected through their 'promiscuous or ill-advised sexual behaviour', or who refused to heed advice not to breast-feed. Where evidentiary problems prevented the use of the child protection legislation, he suggested that the wider powers of wardship be used [White: 1987, 49-50].

Many HIV-positive women were advised not to have children, and, if pregnant, to have a termination. That such recommendations were common in the 1980s and early 1990s is suggested by the findings of many researchers, as well as more anecdotal reports [see Hull-York Research Team: 1993, 72-5, and O'Sullivan: 1992, 235-8].

The Positively Women survey found that:

[d]espite ...that the risks of a woman transmitting HIV to her child are relatively low, nearly half of the women (48% no. 36), stated that they had been pressured either not to become pregnant or to have an abortion [1994, 22].

Many of these women had been diagnosed before 1988. However over 30% of the women diagnosed since 1990 had also been given this advice [1994, 23].

In Edinburgh, medical professionals reported advising terminations or avoiding pregnancy early on in the epidemic [Mok: 1987, 24], although this approach was later criticised by a Glaswegian clinician [Hepburn: 1992, 58] and in a Scottish Home and Health Department report [1992, 641]. Also in Scotland, McKeganey and Barnard found that the HIV-positive Glasgow women they interviewed had been counselled not to have children, or, if pregnant, to have an abortion. Some respondents who had followed this advice later resented it, particularly in light of studies reporting relatively low rates (12.9%) of vertical transmission in Europe [1992, 105-6; also see Thorne et al.: 1996].

Policy Responses to These Fears

The literature review also provided examples of policy attempts to counteract these concerns. The Advisory Council on the Misuse of Drugs [ACMD], for example, also drew attention to drug-using women's fears that their children might be removed, in

trying to explain the lesser use of drug services by women than men [ACMD (II): 1989, 23-4]. With this in mind, the Council reiterated a previous recommendation that:

drug misuse per se should not in itself be a reason for separating parents and children [ACMD (II): 1989, 24].

Several local authorities in London attempted to counteract this fear, and any previous negative experiences of social work, by funding voluntary sector projects for HIV-positive women. Islington Local Authority, for example, recognised its need for the expertise of local voluntary groups in its work with drug users [Association of London Authorities [ALA]: 1991, 10]. Similarly, Camden and Haringey Social Services funded a worker at Positively Women as a shared Community Development Worker, commenting that:

[b]y funding a post in the voluntary sector, the boroughs solved a lot of problems. Many women are suspicious of the statutory services and would be more likely to approach and confide in an independent organisation. And, by siting the post in Positively Women, the [HIV] Unit are now able to draw on a great deal of expertise about all aspects of women and HIV [ALA: 1991, 4].

The worker in this post further confirmed that HIV-positive mothers, including drug users, found it easier, and less threatening to approach this service:

[b]ecause Positively Women is seen as neutral they tend to have more trust in us [ALA: 1991, 4].

Some HIV agencies also tried to reassure women with respect to social work. Leaflets produced by Positively Women emphasised the point that children will not be placed in care, simply because the parents or the child have HIV infection [Positively Women and Immunity: 1993; see also Fletcher et al: 1992]. The Local Authority Associations' Officer Working Group on AIDS also emphasised to its members that HIV-positive mothers may be very anxious that they will be considered unfit mothers, recommending that:

reassurances [...] be given to such women that their children will not automatically be received into care. [...] *Information should be made available by all Departments as to what the rights of women and children are who use the services available to them* [1989, 11 emphasis added].

These recommendations and reassurances do not refer to drug-using parents, however. Since this may be the group perhaps most likely to lose their children, the action taken by Hammersmith and Fulham may have been significant:

policies have been written or revised including childcare guidelines and working with drug-using parents [ALA: 1991, 7].

Glimpses of Other Influences on Service Use

The literature available to me in 1995-7 did, therefore, suggest several important reasons for HIV-positive women's non-use of social services. I was left slightly dissatisfied, however, with the 'matter-of-fact' or practical tone of this literature, which seemed to imply that once a need had been identified, a relevant service provided, and all practical and informational barriers to its use countered, it would be used. Other literature [for example Littlewood: 1994; Carricaburu and Pierret: 1995; Stevens and Tighe-Doerr: 1997] pointed to a lengthy process of coming to terms with the diagnosis. This was not, however, reflected in the literature on service use, with the exception of certain, unexplored comments, discussed below.

Wight et al, for example, made the following comments in their article:

Access problems and financial obstacles are mentioned far less frequently than the PWA's unwillingness to use services, suggesting that *attitudinal or motivational* factors present formidable barriers to service use [1995, 516, emphasis added].

Other studies also provided brief glimpses of other potential influences on service use. Beedham and Wilson-Barnett, for example, noted that:

[a]cceptance of (further) help was also equated by some (16) with 'giving in to' increased dependence and a further 'admission' of illness, to be avoided at all costs [1995, 680].

Similarly, Seals et al., who received a large number of responses to their question ‘what barriers have you encountered to the use of community resources?’ [1995, 501] noted what they termed ‘the fear of admitting one’s illness’ [1995, 504], with respect to using services such as respite care.

Feldman and Crowley also provide hints of a similar reluctance not to use some services because of their symbolism or emotional significance:

Parents may also need support with long-term planning for their children but often have difficulties in acknowledging this or finding the right time to begin the process [1997, 135].

Barrett and Victor suggest another reason for not ‘admitting illness’: the concern that the use of such services may set the user apart from the ‘norm’. They quoted one parent who explained their family’s non-use of voluntary groups in the following terms:

[HIV] hasn’t taken over our lives. We just want to be a normal family [1994, 431].

Similarly, based on her experience working at Positively Women, Gorna comments that:

[I]ntegrating ‘HIV’ into a sense of personal identity is often foreign for women: group sharing (a fairly American practice for a start) may be a totally unfamiliar exercise on top of which is the unnatural act of seeking help for oneself [1996, 147].

These articles therefore suggested the existence of additional complex issues which may affect people’s use of social services, without exploring them further. This is what I decided to do in this study.

Conclusion: Study Aims and Research Questions

In 1995, when I started this study, the available literature reflected the development of concerns relating to HIV infection and AIDS up to that time. The early focus of research had been on prevention and on investigating theories of transmission. The

In the developed world, social services for people with HIV infection were also, if again belatedly, starting to attract attention as, with medical advances, HIV-positive people started to live longer. Literature on the use or non-use of services, particularly by women, was even less available. Where this subject was broached, the main focus seemed to be on practical barriers to service use. Where other issues, such as mothers' fear of social work, were addressed, the tone of this literature remained 'practical', focusing on potential solutions to this problem, such as the provision of services through voluntary agencies, rather than exploring the broader, emotional ramifications of this fear.

Some of the literature, however, did hint at the significance to an understanding of service use of exploring more emotional responses to a positive diagnosis and its potential implications over time, as well as examining the significance to service use of motherhood itself, the effects of socio-economic circumstances, and of the availability of informal support.

The literature review therefore led me to develop several basic research aims and questions taking a broader approach to exploring influences on mothers' service use than that found in the existing literature. It should be noted that in my research aims, and throughout this thesis, the term 'social services' is used in a different way to much of the social work literature. I use this term to refer not only to the services offered by Social Work Departments (in Scotland) or the Social Service Departments (in England and Wales), but also to the broad range of community-based services in both the statutory and voluntary sectors. This term is also used to distinguish these services from medical services.

My main research aims were:

- to gain a historical understanding of the effects on mothers' service use of the respondents' initial and subsequent reactions to diagnosis with a condition, about which medical knowledge is constantly evolving;
- to explore the perceptions, context and timing of service use among HIV-positive mothers;

- to examine how service use fitted into mothers' everyday strategies to maintain their own health and well-being, in potentially difficult socio-economic circumstances, while looking after their children and, potentially, other HIV-positive family members.

These aims were then translated into the following key research questions, many of which might also be relevant to an understanding of service use by mothers with other chronic conditions:

- what were the respondents' general opinions and experiences of different types of medical social services prior to diagnosis, and did they lead to a fear of involvement with statutory or other services, or otherwise affect post-diagnosis service use?
- was the respondents' service use affected by the stigma attached to HIV infection or drug use, and did they feel stigmatised as mothers?
- what were the respondents' initial post-diagnosis experiences of services, and did these experiences affect subsequent service use?
- to what extent, and in what ways, was service use in general, and the use of particular services, integrated into the respondents' sense of a normal life as mothers, or resisted?
- what were the emotional effects of the respondents' socio-economic circumstances and did these affect service use?
- what were the effects on the respondents' service use of the presence or absence of social support for example, from their partners, immediate or extended families or friends?

In developing my analysis of the data produced by the study, I used some of the HIV literature which became available to me after starting this study, as well as literature from other areas, for example on identity, the experience of chronic illness, motherhood and informal support. That came later however. My next concern was to identify methods appropriate to the exploration of these issues.

Chapter 3: Methodology

My literature review proved useful in thinking about potentially fruitful methods to explore my questions about service use in the context of living with a chronic, stigmatised and potentially life-threatening condition, in this case HIV infection.

The majority of existing studies of services and service needs employed primarily survey-type approaches to data collection. In my view, it was more difficult for these studies to capture the potential effects of processes of emotional adjustment to diagnosis on service use.

More influential on my research design were various sociological examinations of HIV transmission [McKeganey and Barnard: 1992; Flowers et al.: 1997], which employed qualitative methods and innovative approaches to recruitment. I decided to adopt a case study approach to this exploratory project, focusing on Edinburgh, a service-rich city with a relatively high prevalence of HIV infection among women. I hoped to try to recruit a small number of respondents, some of whom would be service users, and others not, for semi-structured interviews. I also aimed to introduce a limited longitudinal element to the data, to reflect the uncertainty and unpredictability of living with an HIV-positive diagnosis, and relating this to service use, by interviewing the respondents at two different timepoints.

In the event, the function of these second interviews evolved as a result of my preliminary analysis of first interview transcripts, to incorporate further exploration of first interview themes. Although drawing on literature published since the start of this study [for example Melia: 1997; Seale: 1999; Robson: 2002], this chapter will take a predominantly chronological approach to analysis of these developments. Issues such as recruitment difficulties, the sensitivity of some of the topics raised in the interviews, and the relationship between interviewer and interviewee will also be discussed.

Basic Research Design Decisions

The Adoption of an Interpretative Design

As Robson suggests, the research design employed must be appropriate to the particular research questions identified [2002, 80]. The exploratory nature of my research concerns, combined with my focus on meanings, perceptions and processes relating to service use, suggested an interpretive approach. Seale, among others, suggests that differences between the interpretive and positivist paradigms of research are often over-simplified [1999, 22]. The interpretive paradigm is, however, generally associated with criticism of the idea, associated with positivism, of an objective researcher reporting on a reality existing independently of human perception [Hughes: 1996, 137; Rubin and Rubin: 1995, 32]. In contrast, an important element of interpretivism is its emphasis on the:

subjective understanding of social actors [Hughes: 1996, 93; also see Rubin and Rubin: 1995, 34]

My concern to capture meanings and processes in a little explored area also suggested, although did not dictate, the primary use of qualitative methods [see Rubin and Rubin: 1995, 5], and of a non-probabilistic approach to sampling. Several writers, including Backett, have emphasised that qualitative methods are better suited to understanding actors' meanings and the way people create and structure everyday life [1977, 46; Graham: 1984]. Some have commented on the suitability of such approaches in fields related to this thesis, including the 'lay' theorisation of health [Milburn: 1996; Entwistle et al.: 1998].

Adopting a Grounded Theory Approach

In light of the lack of research data in this area, I decided to adopt a, broadly, grounded theory approach. The aim, therefore, was not to:

over-emphasise the rigorous testing of hypotheses [but to discover] concepts and hypotheses [...] relevant for the substantive area being researched [Glaser and Strauss: 1967, 153].

Paraphrasing Robson, my aim was to generate theory, inductively, from data collected in the study [2002, 90], that is, from a rich exploration of the broader social processes, social context and meanings underlying the use of social services [also see Backett: 1990, 63].

Adopting a Case Study Approach

The exploratory nature of my research questions suggested a case study approach, as opposed to a survey or other design. Although it would be difficult to identify any British location as 'typical' in the context of HIV infection, I thought that Edinburgh in the 1990s might be considered an 'extreme' case for the following reason. At this time, the prevalence of HIV infection among women in the city was relatively high. Bury cites Lothian Health Board figures for 1988:

By 1985, 50% of injecting drug users had become infected, one third of them women [Robertson et al, 1986]. By 1987, not only did Edinburgh have 30% of all women in the UK known to be infected with HIV but Edinburgh also had the highest prevalence of HIV infection anywhere in the UK [1992a, 12].

In addition, Edinburgh was also a service rich location where a range of services was available. The city therefore presented an opportunity of exploring a variety of potentially complex patterns of service use. Importantly, an examination of service use in such a location was less likely to be affected by concerns relating to a lack of services. Put bluntly, it seemed that if respondents did not use service in Edinburgh, they were unlikely to use them elsewhere.

With hindsight, however, I might have tried to recruit in Dundee, a smaller East Coast Scottish city, which for similar reasons, also has a relatively high prevalence of HIV infection, and some specialised HIV services. At the time however, the Dundee agencies had a reputation of being anti-research, and I lacked the funding to make numerous trips to the city.

Deciding to Recruit a Non-Probabilistic Purposive Sample

In the light of the exploratory nature of my planned study, I was aware that I would need to construct a 'purposive' respondent sample, reflective of my aim of gaining

an understanding of the dimensions and dynamics of service use. As Robson describes, this type of ‘theoretical sampling’ is:

undertaken so that additional information can be obtained to help in generating conceptual categories [2002, 193].

A major influence over my initial conception of what might constitute a purposive sample for this study were suggestions in the literature of the existence of a large group of non-users of services, who might differ from service users in terms of their personal or social characteristics, or their life experience.

Based on her experience of Positively Women, a voluntary agency in London, Gorna makes this point with respect to agencies providing ‘social spaces’ for users to meet:

[t]hose who reach out to find others with the same medical diagnosis are often on a path towards ‘victorhood’ [1996, 150-1; also see Rhodes et al: 1994, in Philip et al.: 1997, 96].

Kalichman et al.’s psychological study makes this conclusion with respect to a broader range of services. They find that non-attenders of HIV services are more likely to be recently diagnosed, female, have lower self-esteem, show greater cognitive and somatic depression, anxiety and loneliness than attenders [1996, 593-4].

Some service providers I interviewed also shared this perception of:

large numbers [of HIV-positive women] who’ve disclosed their diagnosis to no-one, while a smaller hardcore move around all the services [representative of Women’s HIV/AIDS Network [WHAN]].

She pointed to the large numbers of inquiries received by WHAN from women, living in rural areas far from Edinburgh, who were very cautious about consulting agencies in person, perhaps out of concern for their own or their children’s confidentiality, or fear of social work intervention.

These sources therefore suggested the importance of contacting non-users of services, in general, and newly diagnosed women, in particular. Similarly, the

literature reviewed in the previous chapter suggests the importance of trying to interview current drug users.

Adopting Semi-Structured Interviewing As the Primary Means of Data Collection

Another initial research decision, made in the light of the questions identified, was to employ face-to-face interviewing, using a semi-structured topic guide, as the primary means of data collection.

I felt that this type of interview would be both sensitive and responsive to the respondents' views and meanings. As Miles and Huberman put it:

the informal atmosphere of the semi-structured interview encourages respondents to be open and honest whilst the qualitative data thereby collected enables researchers to locate the meanings that people place on the events, processes and structures on their lives [1994 in Neale: 2002, 4].

The flexibility of such interviews also allows for the investigation of the meanings of phenomena to the particular respondent. For example, the interviewer may change the order of questions to follow the train of the respondent's thoughts [Robson: 2002, 270-1]. Similarly, the interviewer is able to modify their line of enquiry to follow up interesting verbal or non-verbal responses, and investigate underlying motives [Robson: 2002, 272-3].

The adoption of a survey-type instrument of data collection was considered, but rejected, although I did include some more structured questions to obtain information on the respondents' socio-economic situation and basic service use. Further, many writers' recommendations with respect to the construction of survey questions proved very useful to the development of parts of the topic guide. These included the advisability of using simple language, keeping questions short, and avoiding double-barrelled, leading, ambiguous or negative questions [Robson: 2002, 225-6]. However, the difficulties of using highly structured, survey-type research tools in an exploratory study suggested they were not appropriate here. As Robson emphasises:

[s]urveys work best with standardized questions where it is possible to be confident that the questions mean the same thing to different respondents, a condition which it is difficult to satisfy when the purpose is exploratory [2002, 234].

Similarly, Huby et al. point out in their study of discharge from care, the analysis of complex, and often informal processes, over time, may be difficult to ‘grasp’ by means of a questionnaire [1995, 2].

Another potential option, in light of the sensitivity of some of the issues raised, and the respondents’ likely concerns around confidentiality, might have been to employ self-completion, postal questionnaires [Robson: 2002, 234]. I rejected this option on similar grounds as structured interviews, however. With hindsight, this was a fortunate decision. The respondents proved to be fine talkers, but disliked writing. One respondent explained that she was ‘speaking her life’ into a tape recorder for a friend to write up as:

I know what I want to say, and I can speak it to you, but I cannae put it down.

I also considered, but ruled out, participant observation as an appropriate strategy, since, in the absence of major sponsorship by several agencies, the ‘use’ of social services did not seem observable in a practical or time-effective way. Further, it did not seem possible to observe the non-use of services.

Deciding to Interview Each Respondent Twice

Another early decision was to interview each respondent at least twice, for the reasons discussed in the following sections.

To Obtain Some Longitudinal Data

‘You don’t live in hindsight though, do you? Hindsight is a different light. It makes everything change shape’ [Kay: 1998].

Mayer and Timms discuss several well-known methodological challenges relating to retrospective accounts: the rapid dimming of memories of even recent, personally insignificant, events [1970, 30; Foddy: 1993, 93]; and the effects of more recent

physical and emotional experiences, such as illness, on perceptions of prior events. They discuss the possibility that former users of the agency whom they studied, whose problems subsequently worsened, might be more critical of that agency than would otherwise have been the case [1970: 30]. Similarly, Marsh discusses how an outcome may lead a respondent or researcher to imbue a previous event with a meaning it did not have at the time [1982, 118].

With these problems in mind, I adopted Sobo's technique of 'narrowing the reference period' of several questions:

memories of specific recent sex acts may yield more valid data than self-reported generalisations regarding sexual habits [1995, 119. Also see Converse and Presser: 1986, 20].

For example, I asked first interview respondents to focus on service use over the previous six months. In the second interviews, I asked about service use, as well as other developments, in the period between the interviews.

In another attempt to obtain information focused on recent, specific events, I supplied each respondent with a notebook or diary in which to document their service use between interviews, as well as their feelings about and reactions to these services. This strategy was inspired by Coxon, who considers interviews to be 'vague roundups', and diaries as more natural places to confide private thoughts and feelings [1994, 125-7].

Coxon also raises potential difficulties with this technique, such as self-motivation and the fact that many people are unused to expressing themselves in writing, noting that diary-writers tend to be better educated, more middle-class, 'approval-motivated and sociable' [1994, 129]. With hindsight, these concerns should perhaps have warned me off any attempt to employ this technique. The culture which the respondents preferred seemed to be more oral than written, and none of them wrote anything in the notebooks I gave them, except for shopping lists.

To Obtain the Respondents' Trust

This aim was influenced by Cornwell's East London study of lay perceptions of health. Although she later concluded that her findings might be explained as a 'localised effect' [Seale: 1999, 167], her experience was that, in the artificial and awkward context of a first interview, interviewees responded by putting on their best or 'public' face [1984, 15].

Of relevance to this study was her finding that questions relating to family relationships were particularly sensitive [1984, 93-4]. She concludes that she was only able to obtain more personal or 'private' reflections, after several interviews with the same respondent [1984, 205]. Similarly, Backett suggests that the problem of public accounts may make it advisable to make first interviews less challenging [1990, 65].

These writers' findings prompted my concern that two interviews with each respondent might not be enough to address sensitive issues. With this in mind, before starting each interview, I spent time trying to create a relaxed atmosphere, joking about my recording skills, or about relationships with men if that subject came up, as it often did. As Backett advises, I reassured the respondents that there were no 'right' answers to my questions [1977, 57-8], and determined never to refuse a cup of tea in case this was interpreted as an irrational fear of HIV infection.

Before turning to the topic guide, I also encouraged the respondents to talk freely about what was on their minds. Several respondents had thought a lot about what they wanted to say to me, and I thought it better for them to say it before starting the interview. One respondent was initially very aggressive, but my answers to her questions cleared the air. At this point, I also discussed confidentiality, and emphasised that women should not answer questions they were uncomfortable with, and should ask me not to use any material they regretted disclosing.

In the event, respondents disclosed very personal information in both interviews, and one respondent seemed more forthcoming in her first, than in her second, interview. My fieldnotes do suggest, however, that the second interviews were more relaxed for both parties. I felt more confident asking sensitive questions, and the respondents

seemed less concerned about their own and others' confidentiality, referring to others by name rather than in general terms. Some respondents' homes seemed less clinically tidy on my second visit, and, unlike the first interviews, the second interviews often took place with other people around. R4, for example, was prepared to go ahead, even though her niece, who was unaware of her diagnosis, was in another room. R3's son listened and contributed to the second half of this interview.

To Reflect the Uncertainty of Living With HIV Infection

Boulton points out that a uniquely cross-sectional research design cannot capture changes in attitude [1994, 3]. Similarly, Backett emphasises the dynamic nature of health, arguing that:

[i]t is important to incorporate a time dimension into studies of health in families [...]. On a theoretical level, this approach is a response to work which indicated that concepts of health and health behaviours may have static elements, but may also fluctuate in response, for example, to other changes in people's lives. A further aspect of the dynamic nature of health may be the actual experience of illness, and experiences with health professionals [1990, 61].

Interviews with service providers also suggested the potential influence of seasonal change on respondents' perspectives, highlighting that many of their female clients found the winter (when most of the first interviews took place) a difficult time. Three respondents did in fact complain of the cold and dark in their first interviews, while two second interview respondents expressed optimism at the return of warmer weather.

The major differences in perspectives between the interviews related more to the respondents' health and personal relationships, however. Often these changes were made very obvious at the beginning of each second interview, when I asked respondents what had happened since their previous interview, thus providing them with an opportunity to talk about what was most on their minds.

The use of two interviews therefore introduced a limited longitudinal element into the study, and allowed me to establish a certain rapport with the respondents. Most significantly, however, the use of two interviews was a crucial tool in capturing the

unpredictability of HIV infection, and the potential effects of illness and other concerns on the respondents' attitudes. The contrast in levels of health and optimism between the two interviews was often striking, and will be examined in subsequent chapters.

Preparing the Topic Guide: Interviews With Service Providers

As preparation for my main interviews with actual or potential service users, I decided to interview some Edinburgh social service providers to obtain local information on services to compare with primarily North American or London-focused literature-review sources. This seemed important in light of the great variations in the epidemiology of HIV, in community care priorities and the arrangement of social services, within the UK [Hull-York Research Team: 1993]. I also wanted to tap into service providers' perceptions of 'typical' clients who were HIV-positive mothers. Finally, I hoped that these interviews would help me gain the trust of service providers, facilitating recruitment.

I approached a heterogeneous group of agencies by means of a letter describing the research project, asking for an interview with a representative, and requesting access to a small number of their clients who were HIV-positive mothers [see Appendix 1].

I completed ten, approximately hour-long, interviews, which I recorded and fully transcribed myself, with: three representatives of the Social Work Department, including two practitioners; a GP with a large number of HIV-positive patients; two HIV-specific organisations providing meeting places and a variety of practical services, including benefits advice and alternative therapies; one HIV organisation which provides practical help through volunteers in the community; one agency which focuses on helping children affected by HIV; one agency providing residential services to women with addictions; and one organisation (WHAN) with no direct client contact.

I used a semi-structured topic guide for these interviews [see Appendix 2], focusing on the aims, facilities and resources of each agency, particularly those for women and children; client recruitment; networks of referral and co-operation between

agencies; and their perceptions of the climate of HIV service provision. Where respondents were practitioners, I tried to obtain general information about the HIV-positive mothers whom they had seen as clients in the previous six months.

These interviews proved to be useful preparation for my interviews with HIV-positive mothers in several respects. They confirmed the importance of several issues encountered in the literature review, but also highlighted other matters which I then incorporated into the topic guide. These included the importance of the effects of diagnosis on women's intimate relationships. The emphasis placed by many service-provider interviewees on tensions in the working relationships between, for example, 'child' or 'adult-focused' agencies, also alerted me to the possibility that women might be attracted to different organisational cultures and environments.

The service-provider interviewees' reflections on the different characteristics of their clients, often prompted by reviewing their diaries, also reinforced my concerns with respect to constructing a purposive sample. In particular, the SWD representatives interviewed indicated that their clients, particularly 'chaotic' drug users, were more vulnerable than those in contact with other agencies. They also thought I would find it difficult to recruit drug-using women to the study from other agencies.

Recruitment: The Saga

Successful Recruitment Strategies

Recruitment Through Voluntary Agencies

Whatever the location of this research, the stigma attached to HIV infection was likely to make recruitment difficult. The 'hidden' nature, as well as the heterogeneity of this population, led me to approach as wide a variety of statutory agencies and voluntary social services as possible.

Unfortunately, I was refused access to patients by the City Hospital, the specialist HIV hospital in Edinburgh at the time. The Social Work Department [SWD] also refused me access to its clients, citing previous experiences of journalists posing as

researchers,¹ and producing sensational reports, some of which had breached client confidentiality and undermined clients' trust in their workers. I was also subsequently refused access to social work casenotes on the basis of cost.

As a result, like the Hull-York Research Team [1993], this study drew the majority of its respondents from voluntary agencies, specifically three Edinburgh agencies, and later, one in Glasgow. Recruitment from these agencies was, however, affected by the ambivalence towards research of some workers, who disliked asking clients to participate in studies, in case they came to associate service use with being 'fair game' for research projects. Similarly, they worried that clients' consent, and their trust in the worker-client relationship, might be compromised out of feelings of loyalty, or a misplaced concern that future help might depend on participation in research:

[w]e just feel that there is so much research and it just adds to the women's burden.

[...] The clients feel obliged to help because they are being asked to do so by us, and therefore because of the help they are receiving [service provider interview].

With respect to two of these agencies, I was concerned that worker mediation of the selection process would provide only very confident, articulate respondents, or perhaps those most likely to give a good account of the agency [also see Barrett and Victor: 1994]. Such fears were confirmed in the case of one agency which put me in contact with one woman only, who was on its management committee. She seemed very accustomed to giving interviews, as some of her stories were well-honed. The Manager of this agency was reluctant to allow me access to other women.

Another of these agencies did not want to approach new clients, and was concerned that:

for some reason, there's been quite a lot of women wanting to do work around women in the last few months. [...]I'm trying not to keep using the same women [...]and tir[ing] them out and get[ting] them fed up...there we go, we're just good 'pieces for research' [service provider interview].

¹ I was asked whether I was *The Scotsman* journalist of the same name.

The most co-operative agency was, perhaps significantly, run on a self-help model. I knew from a service provider interview that, at the time, the agency had nine HIV-positive mothers as clients. The names and phone numbers of seven women who had agreed to be interviewed were forwarded to me in July 1997. I was then not ready to interview, as I explained to each of the women on the list. When I phoned them again in October 1997, one had changed her mind, but I interviewed the remaining six. Although the interviews with respondents contacted through other agencies did not reveal a uniformity of approach, it was notable that 'the self-help' women held very diverse opinions. Further, while some of these women were very self-confident, personally and with their diagnosis, others were shy and had never previously been interviewed. Their willingness to participate may suggest that some workers in other agencies may have been over-protective.

Use of Snowballing

In the light of my aim of contacting non-users of services, I decided to employ 'snowballing' as a further strategy [see Cornwell: 1984; Drever: 1995, 36], hoping that personal introductions to potential respondents by friends would prove reassuring. At the end of the first interview topic guide, therefore, I included a question as to whether the respondents knew of other HIV-positive mothers, particularly service non-users who might be willing to participate, and if so, whether they would think about contacting these women on my behalf.

Huby et al. criticise snowballing as a means of trying to contact non-users of services:

[n]on-use of services is often a deliberate decision [...]. Fear of the effects of the stigma associated with HIV-positive status, and a denial of the illness may be important reasons. [...] Asking people with HIV to contact friends or acquaintances whom they knew to be reluctant to come forward and talk about their experiences, for whatever reason, seemed to be an unfair request [1992, 14].

I felt that the decision should be the respondents', but was careful to adopt an 'opt-in' strategy, to avoid exerting any pressure on them. In the event, the interviewees did not experience my request as a burden, and some had contacted HIV-positive

friends about the study prior to my arrival. Two respondents phoned friends while I was at their house, and helped arrange interview times. In one case, an interviewee put some pressure on a friend to meet me, which she resisted.

This strategy was successful in contacting three respondents, two of whom were also identified by a social service agency. However, further contact through snowballing facilitated these interviews, for example, by providing reassurance as to the interview experience, and by providing me with one woman's new phone number.

All of the respondents contacted in this way were, however, service users. This might confirm Philip et al's view that outwith an ethnographic framework:

for women who are making it their business to remain hidden not just from the authorities but also from the community, [snowballing] is deficient [1997, 96-7].

Cornwell's successful use of the technique may therefore relate in part to the fact that that the respondents in her study did not feel stigmatised.

Less Successful Recruitment Strategies

Attempts to Recruit Newly Diagnosed Women and Drug Users

As previously discussed, these were the groups of women most likely to be service non-users, according to the literature and some service providers I interviewed. The importance of contacting newly diagnosed mothers was reinforced by the fact that several of the first few women I interviewed had been diagnosed over ten years previously, but had not used services for some years after their diagnosis. Similarly, SWD representatives I interviewed suggested that their clients, notably current drug users, were particularly vulnerable and marginalised as compared with users of other drug agencies. I therefore re-doubled my efforts to contact women in these 'groups'.

With the aim of recruiting current drug users, and on the advice of interviewees who were former drug users, I contacted several Edinburgh community drugs agencies. Several community drugs workers agreed that current drug users were more likely to use these agencies than HIV services. However, although two drug agencies

indicated that they were willing to help me, they had no clients fitting my criteria at the time.

One of the drugs workers I contacted offered to help me approach the City Hospital to try to recruit newly diagnosed women, as well as current drugs users attending the hospital's substitute prescription service. She used a letter I had produced, describing my project, to advocate in my favour at a meeting with City Hospital consultants. As a result, I was invited by several consultants to write a letter introducing myself and the study to their clients on substitute prescription, who could then 'opt-in' to the study. None did.

Other efforts to contact newly diagnosed and drug-using women were also unsuccessful. On one occasion, I accompanied a GP on a home visit requested by an HIV-positive patient on a methadone prescription. When we arrived, there was a note on the door asking him to leave her a new prescription at the chemists'. On discussion with the chemist, the GP concluded that she had not really been ill, but worried that her methadone prescription had run out, after a recent stay in a residential unit. The difficulties involved in interviewing current drug users were underlined when two current drug users I had arranged to interview in Glasgow, both dropped out on the day of the interview, one of them to enter a drugs rehabilitation unit.

Finally, on the suggestion of my supervisors, I contacted an agency providing practical help, with a recruitment strategy designed to incorporate the way the agency itself works – by phone- into my interview structure. I suggested this strategy might be less intimidating to clients, particularly newly diagnosed women, while respecting the service boundaries of the agency. Interviewees would be able to end the telephone interview by hanging up at any time, with less embarrassment than walking out of an interview. I would not need to know the clients' names, nor even their phone number if a time had been agreed for the call. I could also undertake to destroy any of the phone numbers once used.

The Manager of this agency was, however, unwilling to approve this strategy, suggesting that clients would be too easily 'distracted', and would find it 'awkward'.

She added that ‘people are all over the place’ in the short conversations they had with the agency.

How Purposive Was My Sample?: A Brief Introduction to the Respondents

Twelve respondents were finally recruited, and this section will provide a discussion of the extent to which these respondents’ accounts reflected my aim of getting a better understanding of HIV-positive mothers’ service use in Edinburgh. In the interests of confidentiality, the respondents will be identified by a number, for example R1, reflecting the order of the first round of interviews.

As discussed, I tried very hard to recruit ‘non-users’ of services. Towards the end of my recruitment efforts, however, I began to question the dichotomy I had constructed between use and complete non-use of services. I came to prefer the idea of a spectrum of ‘use’, fluctuating over time, and reflecting different preferences as to the types of service provided. For example, many women might not use agencies providing spaces in which people with HIV infection might meet (referred to in this study as ‘social space’ agencies), but might be willing to phone an agency offering individualised practical help at home.

This reconsideration was influenced by my interview with the Manager of this latter agency. Asked whether HIV-positive mothers were particularly isolated, she responded:

[t]ruthfully I don’t get a sense of that from either group (women/ mothers). They may be limited in where they go. But I don’t get a real sense of many of them being isolated. Not if they have children because [...]they will do their best for their families.

A manager of a ‘social space’ agency agreed that some mothers would contact agencies for services for their children, such as help getting them to school. In light of these comments, I came to consider the absence of ‘complete’ non-users of services as less important. Further, I was satisfied that the respondents recruited do reflect a spectrum of differing levels and types of service use.

All but three respondents were brought up in Edinburgh housing schemes. Their 'home' areas were as follows: NW Edinburgh: 4; NE Edinburgh/ Leith: 3; SW Edinburgh: 1; Central Edinburgh: 1; Midlothian: 1; Fife: 1; Glasgow (East End): 1. Only one more 'middle class' woman was interviewed, but it is argued that this sample is broadly reflective of the social backgrounds of HIV-positive women in Edinburgh in the 1980s, and the close association of HIV transmission with intravenous drug use on the city's peripheral housing schemes. Six respondents had previously had problems with heroin use. One of them had stopped using street drugs relatively recently, while three were receiving substitute prescriptions. While no current drug users were included in the study, therefore, several respondents did have direct experience of the effects of drug addiction on service use. Further, some community drugs workers I spoke to emphasised that few HIV-positive mothers continued to use hard drugs.

Seven of the respondents had one child, four respondents had two children and one respondent, three children. The children's ages reflected a broad range: 7 (1 child); 8 (3 children); 9 (2); 11 (3); 13 (2); 16 (1); 17 (1); 18(1); 19(1); 21(2); 22(1). The study therefore explores issues relevant to the service use of mothers with children of varying ages.

The respondents' health status also varied. Three described themselves as having AIDS, one of whom was to be officially discharged from hospital the day after the interview after serious illness. Another respondent had been diagnosed as having AIDS, according to a previous definition. While six respondents were being prescribed combination therapies, four others had never experienced any HIV-related illness. Bearing in mind the comments of SWD representatives that their clients were more vulnerable and marginalised than those of other agencies, it should be noted that several respondents had previously had social workers. At the time of the interviews, two respondents had children and families workers, while two others had community care workers. Experiences of such difficult periods were therefore reflected amongst the respondents without dominating the sample.

The respondents' ages varied between 26 and 44 at the time of their first interviews. They had known about their diagnoses for 7-13 years. The years of their diagnoses

were as follows: 1985 (2); 1986 (5); 1988 (1); 1988/9 (2); 1989 (1); 1990 (1). A GP I interviewed was impressed that I had interviewed a woman diagnosed as recently as 1990. This study can therefore make no claim to reflect the experiences of newly diagnosed women.

Comments Relating to the Content, Structure and Conduct Of Both Interviews

The first interviews took place between 30 October 1997 and 6 April 1998. Written consent was obtained from all of the respondents, and it was emphasised that they should feel no pressure to complete the interview, nor to answer questions they found upsetting. Five interviews took place on the premises of different social agencies. Seven were conducted in the respondents' homes, providing further insight into their circumstances, and helping to put the respondents at ease.

The respondents were usually alone during the interviews. R12 insisted on a worker being present. This may explain the extremely positive general comments she made about various services, since these were sometimes contradicted by her answers to more specific questions. The presence of others during some other interviews provided interesting insights. For example, the presence of R10's hyperactive young child allowed her to emphasise how tired she was.

As I expected recruitment to be difficult, I was concerned not to exclude any interviews from the main sample as 'pilots'. Instead, I decided to assess the first two or three interviews particularly carefully, hoping that no major amendments would be required. In the event, I made very few alterations to the topic guide, apart from re-phrasing any questions which might be interpreted as tests of integrity.

Often the respondents did raise issues, covered by my questions, in the initial discussion period. I used this opportunity to discuss these matters there and then. Whether or not this occurred, I found that the interviews flowed well. The division of the topic guide into two parts was also helpful: the first focused on the respondents' personal history, current circumstances, and difficulties associated with their diagnosis; the second contained more structured questions as to the respondents' knowledge of available services, their use of services in the previous

six months, and their opinion of these services. Structuring the first interview topic guide [Appendix 3] in this way fulfilled my aim of setting the respondents' service use in its emotional and historical context. This structure was also generally successful in ensuring that the interviews finished on a less emotional note. I hoped that this might protect the respondents a little from dwelling on more painful issues after the end of the interview.

Given the respondents' diagnosis, I was also concerned that the interviews should not be too long. Before the interviews, therefore, I prioritised questions, identifying those I would omit if the respondent became tired. In the event, the topic guides for both interviews seemed of an acceptable length and I used all the questions. The only partial exception to this was my first interview use of 'flashcards', to elicit a more spontaneous response to different agencies which could then be compared with answers to questions on recent use of the agencies, potentially revealing complex, ambivalent attitudes to them [see Foddy: 1993, 93]. The cards, which I often handed over to the respondents, bore words such as 'caring', 'warm', 'judgemental', 'have strings attached' and 'comfortable with HIV'. While several women enjoyed this (and this technique was particularly useful with one taciturn respondent), others became impatient. I decided to retain these cards, but not to ask subsequent interviewees to use them to describe all of the agencies they had used, but only those they used most frequently.

All of the first eleven respondents seemed to enjoy the interview, and signed consent forms, allowing me to contact them to arrange a second interview. In the event, it was not possible to organise second interviews with four respondents: one woman had moved and was uncontactable; another had started full-time work and felt that she would be too tired to participate, despite my efforts to persuade her; one respondent had become very ill by the time of the second interviews, and although I left several messages for her through an agency she had previously used, she did not respond. A fourth respondent did initially agree to meet but did not come to the agreed meeting, as her child was ill. I phoned her twice subsequently but she refused, perhaps influenced by her partner whose voice I could also hear. As she had been very ill, I decided to avoid such difficulties with the last respondent recruited,

by combining elements of both interviews, into the topic guide for my only meeting with her.

Second interviews took place with seven respondents between 1 April 1998 and 20 May 1998, each in the same place as the first interview. There was at least a sixteen week, but more typically, a twenty week gap between the two interviews.

Although, as discussed below, the function of the second interviews was expanded as a result of my preliminary analysis, much of the second interview topic guide was similar (see Appendix 4) to that of the first interviews, in order to fulfil my aim of collecting some concurrent data, for example in relation to service use and health status. The topic guide was amended slightly after the first second interview to reflect an important influence on this respondents' early service use: the existence of a family HIV information-exchange network.

The Results of the Interview Process

The first interviews lasted between 65-115 minutes, while the second interviews ranged from 45 to 120 minutes. Most interviews tended towards the longer end of these ranges, although, on average, the second interviews were slightly shorter than the first. The fact that towards the end of the first interviews, the respondents started to raise many of the same issues suggested that a satisfactory level of data 'saturation' had been attained. The next sections will examine the process of data analysis, and the inter-relationship between this process and the development of the second interviews.

Trust Me I'm a Researcher: The Process of Analysis

As discussed, I adopted a broadly grounded theory approach in this study. For Seale:

[g]rounded theorizing represents a particular version of the link between data and theory statements, emphasising their interdependence and proposing that theory can in fact be generated from close examination of the data [1999, 88].

In much methodological writing, particularly on experimental, but also some on qualitative research designs [see Silverman: 2000], the link between theory and data

is discussed in terms of validity (internal and external) and reliability. In this study, however, the concern to document the quality of data analysis will be assessed with a view to establishing the ‘trustworthiness’ of my research practice and data interpretation. This is the criterion adopted by Seale, among others, who approves of ‘fallibilistic’ approaches underpinned by a:

self-questioning methodological awareness [1999, 20].

The idea of ‘trustworthiness’ necessarily implies a ‘strong authorial presence’. As such, Seale presents it as an alternative to the post-modern refusal to privilege any account, including that of the author [1999, 13]. In Melia’s view, at its extreme, the post-modern emphasis on discourse, rather than structure or content, undermines the use of interviews as a means of data collection [1997, 29]:

[a]re the data to be regarded as straight accounts of the interviewees’ experiences or stories about that experience told as an exercise in self-presentation by the interviewee? [1997, 30].

In this study, I adopt the pragmatic approach of Seale:

although we always perceive the world from a particular viewpoint, the world acts back on us to constrain the points of view that are possible [Seale: 1999, 26].

The respondents’ accounts are not viewed as the ‘gospel truth’. To some extent, they may reflect the crystallisation of previous experiences. They will also reflect the respondents’ concerns for self-presentation with respect to particularly sensitive issues.

In Melia’s words, my overall aim is to tell a plausible story [1997, 30], adopting her admonishment:

to be less epistemologically squeamish and get on with it [1997, 30].

With this, and Seale’s strictures in mind, the following sections will present evidence as to the way I conducted my analysis:

seek[ing] to empower readers to make their own judgements about the credibility of the story told [Seale: 1999,178; and see his checklist: 189-192].

Obtaining and Maintaining a Good Knowledge of the Data

My knowledge of the data was facilitated by several factors. Completing the interviews myself was invaluable with respect to obtaining:

taken for granted knowledge that is not expressed in words [Backett: 1977, 54].

Tape-recording the interviews allowed me to pay closer attention to what was said, and to note non-verbal cues, including intonation [Robson: 2002, 290]. Similarly, the process of fully transcribing the interviews myself:

offer[ed] an extra opportunity to relive and reflect on the discussions [Backett: 1977, 54].

Throughout the process of analysis and writing-up, I continued re-reading the interview transcripts in the light of new possible interpretations, a process aided by my first degree training in literary criticism. This approach may reflect the 'spirit' of grounded theory research, distilled by Seale as:

a rigorous spirit of self-awareness and self-criticism, as well as an openness to new ideas [and] continual revision and development as new evidence, or voices, emerge [1999, 104].

Or as Backett puts it:

The process of analysis is a constant reflexive process of checking concepts and hypotheses against data which do not fit and refining the initial concepts [1990, 64].

Ensuring Consistency in Breaking Down the Data

Many writers refer to the process of slicing up the data into various themes and concepts, or 'coding', as:

the core physical activities of developing analysis [Lofland and Lofland: 1995, 186; Strauss and Corbin: 1990, 61].

Mason describes initial attempts to do this as a process of ‘bland’ ‘signposting’, producing descriptive categories for further refinement [1996, 111]. Several writers provide lists of initial questions to ask of the data, for example Dey who starts off with ‘who? what? when? where? why?’ [1993, 83-4] which proved useful in getting to know the data [also see Corbin and Strauss: 1990, 78-80; and Lofland and Lofland: 1995, 186].

As discussed, this study used a generally grounded theory approach. I did not however apply Corbin and Strauss’ regimented approach to data analysis in the form of open, axial and selective coding with the aim of producing a single ‘core’ category [1990]. As Melia points out, this approach has been rejected by Glaser, the other co-founder of grounded theory with Strauss [Melia: 1997, 32]. She prefers Glaser’s emphasis on the importance of the ‘constant comparative method’ or, more prosaically:

the repeated comparison of information from data collection and emerging theory
[Robson: 2002, 193].

In this study, initial analysis of the data suggested that the respondents had often not used services for many years post-diagnosis, and that subsequent use might be affected by very diverse events or circumstances, such as caring for a dying partner, bereavement, or drug use. Particularly useful in considering ways to compare between, and understand, the inter-relationship between disparate elements of the data were some writers’ identification of ‘non-cross-sectional’, or more chronological or process-oriented approaches to analysis. These included case studies, stories and narratives [see Mason: 1996, 111-131], the results of which may then be compared with those of cross-sectional analyses [1996, 129-130].

Further examples include Lofland and Lofland’s use of visual diagramming and flow-charting to trace relationships and processes through the data [1995, 129-135]. Dey also advises reading and re-reading the data looking for processes, sequences, change, transitions and turning points [1999, 84], as well as settings, activities, events, strategies and relationships [1993, 83-4]. He also suggests using map-type diagrams to try to pull ideas together [1999, 91].

In particular, however, I was influenced by Mason's use of chronological and biographical approaches to opening up data for analysis, and of understanding intricately interwoven elements of data [1996, 129]. I decided to construct chronologies or 'time-lines' out of the first interview data to trace some of the events and circumstances which may have influenced interviewees' service use. As Mason points out, the general form of chronologies is linear [1996, 133]. These time-lines were, however, primarily employed to examine interactions, for example, between events such as those mentioned above, and service use. In my view, the construction of these time-lines facilitated numerous, complex comparisons across the data, as recommended by Lofland and Lofland [1995, 202]. The construction of these time-lines also ensured a level of consistency of analysis, since once a particular circumstance had been identified as important to one respondent's service use, I would re-read the other transcripts to check whether it also seemed relevant to other respondents.

The aim of ensuring consistency of analysis, while identifying numerous potential influences on service use, might have been facilitated by using computer analysis programmes. At the time I made the decision, several writers criticised the use of computers in analysis. For Lofland and Lofland, their use was:

physically and intellectually confining [1995, 201; also see Agar: 1991].

Mason argued that computer programmes hinder progress by encouraging the development of too many initial categories or codes [1996, 125]. More fundamentally, she suggested that computer functions may often support the logic of variable analysis, undermining the adoption of an ostensibly qualitative approach to the data [1996, 117-8, 121].

In contrast, in Dey's view, computer programmes can help to examine data non-chronologically, in the sense of removing the precedence of the first interview [1999, 87], or:

taking different tracks through the data, focusing on key words or phrases and reading around these to produce a different perspective [1999, 88].

In my view, it might have been fruitful to use a qualitative data analysis package such as Nud.ist, to carry out some of this analysis, without falling into the pitfalls identified by Mason. In addition to emphasising the consistency which may be obtained across large amounts of data through the use of such programmes [2002, 462], Robson points out that Nud.ist's employment of a 'tree' structure, made up of individual 'nodes' to represent distinctions drawn between themes in the data does not have to be used in a hierarchical manner. Rather, nodes may be:

entirely unstructured, or be in a flat non-hierarchical structure; or some may be left free-floating while others are linked in a tree [2002, 466].

Unfortunately the lack of university resources, at the time, made the use of such a package unfeasible. This omission may, however, have been compensated for by my detailed knowledge of the transcripts mentioned above. As Dey puts it, computer analysis is no substitute for knowing the data well [1999, 88].

Moreover, with respect to ensuring consistency of analysis, I also employed further strategies recommended by Silverman to ensure consistency of analysis, namely the use of 'simple counting techniques'. For example, the following substantive chapters will often point to the number of respondents for whom the particular events or circumstances were also important [2000, 185].

The Evolution In Function of the Second Interviews As a Result of This Analysis

Earlier in this chapter, I set out my initial reasons for interviewing the respondents twice. However, my analysis of the first interview data led me to extend significantly the intended function and content of the second interviews, to further examine recurrent themes suggested by this analysis and by my construction of time-lines. This development was not conceived of as an attempt at 'member validation' [see Bloor: 1997 for criticisms of this approach]. Rather, it reflected Backett's experience of a dynamic relationship between data and methodology where multiple interviewing is used:

[g]rounded analysis of these transcripts is an integral part of the fieldwork process, as themes and ideas from earlier interviews influence the content of the later sessions [Backett: 1990, 60].

One example of these recurrent embryonic themes was that respondents' service use might be preceded by an often lengthy process of, what I then conceptualised as, 'acceptance' of their diagnosis, influenced by a range of circumstances. Other such themes included the emphasis of some respondents on surviving until their children reached adulthood, and the potential influence of family information networks, suggested by second interview pilots.

The incorporation of these themes into all of the second interviews was accompanied by a degree of customisation to each respondent, since, in some cases, they were asked to comment further on what they had told me in their first interview, while, for others, these were new issues.

The respondents' second interviews were further individualised by the introduction of the time-lines discussed above. I handed these over to the respondents for their comments, while probing further as to influences on their service use. I was initially concerned that this exercise might prove depressing, or that the respondents would consider it presumptuous on my part. Most respondents, however, enjoyed this process, often poring over the time-lines for a while and pointing out necessary amendments. In this respect, my use of time-lines incorporated a degree of the 'mutual endeavour' appreciated by Parry et al. [1999] in their use of the 'life grid'.

Ethical Considerations and the Sensitivity of Issues Raised

Throughout the research process I was acutely conscious of the need to protect the respondents' identities. Before starting each interview, I raised the issue of confidentiality. Several respondents emphasised that this was of great concern to them, a point reinforced during one of the interviews. On this occasion, the respondent blanched and held her head in her hands when she thought a neighbour was listening through the letterbox. Fortunately, it was a false alarm.

As a result of this episode I prioritised my efforts to protect the respondents' identities as far as possible. Conscious that the HIV-positive population in Edinburgh is small relative to the overall population, I took several steps while writing up to disguise the respondents' identities. For example, the number, gender, and initial of their children have often been altered. I decided not to integrate the respondents' accounts across different themes addressed in this thesis. Similarly, I have referred to each interviewee by a number rather than a pseudonym as a further disincentive to re-constructing each respondent's individual story. I have also removed any further details, which, although interesting, might have identified the respondents.

Throughout the study, I was also aware that the interviews would, inevitably, raise some very sensitive issues. I was, therefore, particularly concerned by points raised by feminist researchers, as to power relationships between the researcher and those 'researched'.

Davis, for example, criticises research which subjects interviewees to 'inquisitions', without being 'mutually informative' [1992, 40]. Partly due to recruitment difficulties, but also the constraints of a PhD, I did not obtain respondent feedback on my research design or findings. Further, in the light of the difficulty of maintaining security in offices shared with a changing population of students, I shredded all of the contact details, which would have allowed me to do so, soon after the second interviews.

Standing emphasises that the use of semi-structured interviews allows respondents some power to direct the course of the interview [1998, 189]. I found this to be true to a degree. For example, many respondents' interviews started with them talking about what was on their minds for up to ten minutes. This often led me to change the order of my questions to response to the concerns they prioritised. As discussed, physically handing over flashcards or time-lines also altered the dynamic of the interview, to some extent, with the respondents taking more control.

My concerns about my position as the researcher led me to worry about asking some questions, for example about the respondents' sexual relationships since diagnosis.

In the first two interviews, I became so uneasy before asking this question that I 'bottled' it. My unease was partly provoked in the first interview by the respondent's grief for a partner. However, I was also troubled, more generally, by the presumption of asking such intrusive questions, and was concerned that asking them might constitute some kind of abuse of power.

In discussion with my supervisors, it was suggested that I should analyse the reasons for my discomfort. I concluded that my concerns partly related to adjusting to a new interview situation. As a solicitor, asking sensitive questions was also difficult, but felt more justified by the potential outcome: for example, helping clients to obtain a better standard of living. I was also concerned not to reinforce any perception, possibly created by the respondents' experience of the benefits system, that they should feel obliged to answer intrusive questions.

Ultimately, I came to agree with my supervisors who argued, from experience, that many people are willing to talk about their sexuality and other sensitive or distressing issues. On reflection, the first two interviews provided support for this stance. The second respondent mentioned sex and condom use in response to a very general question. Similarly, the first respondent emphasised the current crisis in her social support network. Although a raw and painful subject, she returned to it constantly, often in response to unrelated questioning. In subsequent interviews, many more, ostensibly sensitive issues were discussed. My supervisors initially balked at my plans to include questions relating to whether respondents had aimed or were aiming to stay alive until their youngest child had reached the age of 16, in the second interviews. This concern was, however, raised in very matter-of-fact terms by several respondents in their first interviews, and by another respondent, without prompting, in her second interview.

This willingness to talk about difficult issues suggests that respondents may use interviews as a kind of 'safe space' to discuss issues with someone who has no power to take decisions concerning their own or their children's lives. The first respondent's answers to later questions on the advice she would give to newly diagnosed mothers indicated that she regretted pouring out her troubles to a professional with such power. Similarly, another respondent expressed her

annoyance at a professional's probing questions on her relationship, but showed no sign of discomfort at my questions, chatting away about it, without prompting, at the beginning of the interview. At the end of an interview, another respondent reflected that she often refrained from discussing painful issues with family members to avoid putting strain on them. However:

It helps me talking as well sometimes, you know sometimes you put the past in the past, but sometimes it doesn't do any harm to go over it and you know sortaehopefully realise how lucky I am (R4).

I therefore decided to ask all the questions I had devised, and found that none of them were perceived to be offensive. Nor did I suspect that any of the respondents would have had any difficulty objecting to the questions, had they found them to be so. In fact, with hindsight, I wondered whether I should have asked some more questions about the respondents' intimate relationships.

Finally, Standing associates the primary power of the interviewer with being able to 'translate and interpret' respondents' accounts [1998, 189]. In this study, I have reproduced a lot of material verbatim from the transcripts, although I often omitted 'you knows' or 'ehms' out of concern for the word count. I felt that converting the respondents' accounts into 'standard English' would detract from their impact and would somehow be disrespectful. With hindsight, however, Standing may be correct that not converting quotations into 'standard English' may devalue their comments in the eyes of many academic audiences [1998, 190-3].

Conclusion

My aim was to complete an exploratory case study of the processes and meanings associated by a group of HIV-positive mothers, with their use of HIV-specific social services in a service-rich location (Edinburgh). I tried to employ the recruitment and research methods most appropriate to this aim. With some exceptions, I feel that I was successful in this.

With hindsight, I was perhaps over-influenced in my choice of recruitment strategies by the emphasis in the literature on HIV-positive people as a 'hidden population',

neglecting some more straightforward approaches, unmediated by gatekeepers, such as advertising in targeted local newspapers. As expected, recruitment was a struggle. I tried various strategies to recruit respondents who would reflect my initial conception of what might constitute a purposive sample, to examine the use and non-use of services by different 'groups' of HIV-positive mothers. I did not, however, succeed in recruiting any recently diagnosed women, any current drug users or any service non-users.

The sample I did recruit was composed of 12 women whose views and understandings had been moulded by living with HIV infection for some time. Over time, my initial concern at not recruiting any service non-users, was tempered by the comments of two service provider interviewees, and my own initial analysis of the respondents' first interviews. I came to see service use less as a dichotomy between use and non-use, and more as a spectrum of different frequencies of use of different types of services. I felt that the respondents reflected a broad range of positions on this spectrum.

The primary method of data collection employed –semi-structured interviews with HIV-positive mothers - elicited rich, exploratory data. In retrospect, it might have been useful to observe a meeting of a women's group at one of the HIV-specific agencies, to gain an insight into the development and crystallisation of different ways of speaking about aspects of living with HIV infection, as a result of collective group interaction [see Kitzinger: 1994; Robson: 2002, 286]. This would have provided an interesting, additional perspective to the research.

The quality of the data generated by the study was, however, enhanced by the use of two interviews. This strategy served my original purposes of introducing a limited longitudinal element into the study, providing for a relaxed atmosphere for the discussion of sensitive issues, and reflecting the unpredictability of living with HIV infection. The latter aim was particularly well-served by this strategy, as in some cases, the respondents' outlooks and appearances were radically different in each interview, as a result of changes in their personal circumstances or their health.

The content and function of the second interviews developed over the course of the study, as a result of the high level of intermediate data analysis carried out between the two interviews. That this analysis influenced the content of the second interview topic guides illustrates the contribution to this study of a dynamic relationship between data and method. One of the more successful tools of this analysis was the construction of customised time-lines for each of the second interviewees. This provided a means to map the respondents' service use onto other events in their lives. These time-lines were examined by the interviewees, who enjoyed this different type of involvement in the interview, and also provided a basis for reflection on other issues. In my opinion, the second interviews were very successful in developing a deeper understanding of recurrent first interview themes.

Overall, my approach to analysis was characterised by a commitment to reading and re-reading the transcripts in light of new and contrasting potential interpretations. Many excerpts from the interview transcripts are included in my examination of these issues in the following chapters. Seale recommends this strategy, with reference to his concern for 'trustworthiness' [1999, 99], as a means of allowing the reader to gain a flavour of the data as a whole [1999, 185]. This approach also reflects my concern to reflect what was said to me, and the way it was said.

The writing-up process threw up further issues for analysis. My initial emphasis on the relevance of a process of 'acceptance' of the diagnosis to the respondents' service use evolved into a concern to explore the inter-relationship between service use and different aspects of the respondents' identities. This will be the subject of the following chapters.

Chapter 4: Regeneration: Renegotiation of Identity Post-Diagnosis

Diagnosis with HIV infection exposes an individual to numerous potential and actual losses, and to uncertainty in many areas of their life. As Pierret describes, being HIV-positive and asymptomatic, for example, is a peculiar state, characterised by the appearance of health but also the anticipation of serious illness, even death [1997, 100]. My analysis pointed to an ongoing process of re-negotiation of identity over the years in response to this diagnosis and its implications, often involving initial denial of the diagnosis, followed later by different understandings of living normally with the diagnosis. This difficult process will form the subject of this chapter.

As discussed, chronological analyses of the transcripts proved useful in understanding the respondents' accounts of the impact of their diagnosis on their self-concept and expectations for the future. My analysis, in this and subsequent chapters, also draws on different strands of the prolific sociological literature on living with chronic illnesses which initial analysis indicated might be relevant [Bury: 1982, Charmaz: 1983, 1987, Corbin and Strauss: 1987, Mathieson and Stam: 1995; Kelly and Field: 1996, 1997; Williams: 1996, 2000]. These approaches have also been applied specifically to living with HIV infection [Carricaburu and Pierret: 1995, Chapman: 1998, Pierret: 2000, 2001, Bartos and McDonald: 2000, Ezzy: 2000].

Perhaps the most influential of the notions discussed in this literature is 'biographical disruption' [Bury: 1982], and most of these authors explore varying relationships between biography and illness. In my analysis I discuss these ideas with reference to the respondents' identities. The idea of identity is also important in some of these writers' work [Charmaz: 1983]. Often however, the term 'identity' is associated with debates between British, Kleinian psychoanalysts [see Craib: 1998] and 'subject-of-language', often post-modern theories of the self [see du Gay et al: 2000]. Both of these approaches, particularly the post-modern [see Bourdieu: 1984 in du Gay et al: 2000, 297], criticise the very notion of biography, and it is important to note that these debates are not the subject of this thesis.

With few exceptions [Petchey et al.: 2000], service use has generally not been a focus of sociological analyses of living with chronic illness. On the contrary, analyses of service use have often adopted an unproblematic conception of need, assuming that once a need is identified, and a service provided, it will be used. Little attention has been paid to the symbolic meanings of services to users. It is argued here, however, that an appreciation of the way in which particular services can or cannot be incorporated into a potential users' identity is crucial to an understanding of why HIV-positive individuals come to use, or not to use, the services available.

Basic Literature on Initial Reactions to Chronic Illness and Identity

As indicated, many of the academic debates on the relationship between illness, narrative and biography have developed around Bury's concept of chronic illness as a 'biographical disruption'. In his view, chronic illness leads to the disruption:

not only [...] of structures of explanation and meaning but also of relationships and material and practical affairs [1982, 175].

Taken for granted assumptions about the body and life course will also be undermined.

In Charmaz' view, this disruption is primarily associated with a 'crumbling self-image' [1983, 168] as a result of the realisation that:

images of self reflected to ill persons by others are inconsistent with their core self concepts [1983, 170, also see Wortman and Dunkel-Schetter: 1979],

and may be wholly incompatible with that person's criteria for possessing a valued self [1983, 170]. Social isolation resulting from the physical restrictions imposed by illness, as well as stigma, may further reinforce this sense of loss of self:

since selves are ordinarily situated in networks of social relationships, social isolation fosters loss of self [1983, 172, 176].

Other writers emphasise feelings of being sullied, and marked out as such, by illness as common responses to diagnosis. Mathieson and Stam suggest a concept of

‘bodily disruption’ to reflect their respondents’ feelings of being ‘contaminated or branded’ [1995, 293-8] by their cancer. Several authors report similar effects on the self-image of HIV-positive women. Stevens and Tighe-Doerr indicate that some respondents felt ‘infectious’ and ‘polluted’ [1997, 526]. ‘Deviant’, ‘contaminated’ and ‘disease-ridden’ are the self-perceptions reported by Crawford et al.: [1997, 3]. Chapman further analyses losses in body-image, intimately associated with self-concept and identity, connected both to the diagnosis itself and medical care:

The regular checks on T-cell counts and viral load act as constant reminders of the action of the virus in the body; linked to this is the idea of pollution where every blood cell contains the potential to pass on the virus to someone else. Finally, body-image disruptions which affect the face, hands or genitals may be particularly distressing and these are areas often attacked in HIV illness [1998, 179-80].

Some writers have criticised or suggested modifications to Bury’s concept of ‘biographical disruption’ from a variety of perspectives. Kelly and Field, for example, argue for the need to place greater emphasis on the effects of illness on the body as the ‘defining characteristic’ of this disruption [1996, 254].

Williams [2000] reviews several other criticisms of Bury’s concept of chronic illness. These include its emphasis on illness in adulthood, and consequent neglect of the undeniable effects on identity of childhood illness, since the latter will not lead to any kind of biographical shift [49-50]. Since the respondents in this study are adults, this criticism is less pertinent here. More relevantly, however, other writers have suggested that in conditions of adversity, old age and material deprivation, many types of crises, including chronic illness, may be considered ‘normal’ [2000, 50]. Ciambrone [2001] emphasises that in the long-term at least, HIV infection might not be the greatest disaster to affect the lives of her sample of poor, American women, many of whom had also experienced domestic violence, racism, drug addiction or the loss of a child. As Williams summarises:

the biographically disruptive nature of illness is perhaps most keenly felt amongst the privileged rather [than the] disadvantaged segments of society [2000, 50].

Bury does not only focus on initial disruptions, however, but argues that they will be followed by the 're-thinking of a person's biography and self-concept', or the reconstruction of identity [1982, 169]. He calls this process of revision and reconstruction of identity 'biographical work':

a central component of [which] is to construct or reconstruct and maintain a sense of personal integrity in the face of radical disturbance of [...] normal identity and [...] customary routines and relationships. This can be broken down into three sub-tasks: maintaining perceived control; maintaining positive self-concept; maintaining a sense of normality [handily paraphrased by Petchey et al.: 2000, 234].

The terms 'work' and 'task' underline the fact that the renegotiation of identity is not a smooth development but is affected by fluctuating circumstances, and under constant review. As such, it differs from the notion of cognitive control or 'adjustment' emphasised in psychosocial literature [Bury: 1982, 168; Mathieson and Stam: 1995, 285].

For Bury and others, this process involves the mobilisation of different types of resources, such as cognitive, material, physical and relationship resources [Pierret: 1997, 105]. Pierret herself, working on HIV infection, finds that some of these resources may already be in existence, drawn, for example, from collective identities as gay or haemophiliac men, a process she describes as 'biographical reinforcement'. Other resources will need to be created over time [1997, 105].

Mathieson and Stam emphasise the importance of narrative in this process of re-interpretation:

in negotiating their way through regimens of treatment, changing bodies and disrupted lives, the telling of one's story takes on renewed urgency. In the end they are more than just 'stories' but the vehicle of making sense of not an illness, but life [1995, 284].

Their analysis comes closer to that of writers who emphasise the importance of these narrative processes themselves in constructing the experience of living with chronic illness, or as Williams paraphrases it:

biographical disruptions's role in the creation of chronic illness [2000, 41].

The sociological literature on the experience of chronic illness therefore provides a fertile source for the analysis of data produced in this study. The next sections will focus on the use I made of these evolving theories in interpreting the data.

How Far Was This Literature Reflected In the Transcripts?

My interpretation of the respondents' transcripts suggested that Bury's and Charmaz' emphasis on 'biographical disruption' and a 'crumbling self-image', respectively, were very relevant, particularly with respect to the initial periods after diagnosis.

Nearly all the respondents described the period after their initial diagnoses as being very difficult. Often very isolated, many of them had experienced feelings of depression and low self-esteem reinforced by the stigma attached to HIV infection.

R2's first reaction was fear. Like many of the respondents, she had been told she was likely to die within a few years, if not months, of her diagnosis. The lack of compassion shown to her at diagnosis had affected her greatly. Her account also reflected what Mathieson and Stam term 'bodily disruption':

I was terrified out of my wits [...] I just couldn't believe that I was gonnae die because[...] that's what I thought was gonnae happen [...]all the stigma that got attached to it [...] I just felt like a leper so [...] I went inwards rather than my normal bubbly cheery self um... a lot of people's attitude towards you, so ignorant....[...], sometimes they make you feel like dirty and no actually talk to you, so you lose your self-confidence, you lose your self-esteem really, you think you're worthless at times, well that's the way I used to feel.

If her choice of words reflected her subsequent analysis of this initial reaction, the feeling conveyed was still raw. Similarly, R3's account provided a striking contrast to her confident, assertive self-presentation at interview:

I was so terrified [...] really scared [...] running from the house to the youth club with the bairns and running all the way back and being quite agoraphobic, ken, but I had to go out for their sake. But at the same time I just sat in and wrote poems and gret all the time [...], I did for a long time.

R6, R9 and R12 also related their feelings of depression and loss of confidence after diagnosis. R9 described this initial period as:

two years of madness, a year and a half of balancing all this out in my head.

Her comments reflected Chidwick and Borrill's finding that, for many respondents, the first few years post-diagnosis were the most difficult [1996, 280]. R12's account indicated that these feelings could, however, persist for much longer. She had only recently started to use services, but described the period between diagnosis and service use as one in which she:

Didn't have any confidence in myself at all. I hated myself.

Her interview also indicated that her new-found more positive self-perception was fragile. Twice in her interview she said that her infection was not her own fault, but she also described herself as having ruined her 'whole life' by taking drugs.

A common early post-diagnosis reaction reported by the respondents was to try to exclude HIV from their thoughts, and their self-perception, and to carry on as before. They were determined, therefore, not to allow HIV to become part of their identity. R9, for example, mentioned her ultimately unsuccessful attempts to 'switch off' her diagnosis in her mind. R7 indicated that she did not think about the diagnosis for the first ten years. Other respondents, including R10 and R11, described this reaction in terms of pushing the diagnosis to the back of their minds, while R11 also spoke of a period of 'denial'.

R12's account highlighted the effort required to ignore the diagnosis:

for the first 4 years I just totally denied it, I didn't pay any attention to it. Cos as far as I'm concerned you have a conscience and an inner conscience and my conscience was just 'I've no got it' But I'm aware of this wee voice at the back of my mind, my inner conscience was waiting all this time saying 'you have got it and you need to take tablets and you need to do this'.

In the psychosocial literature on HIV infection, 'denial' is considered to be a 'maladaptive coping strategy' [Lutgendorf et al.: 1994; Pakenham et al.: 1994;

Clement and Nilsson-Schonessen: 1998]. R12 also implicitly criticised this strategy in other women she knew to be HIV-positive, but not in contact with any HIV-specific services despite her efforts to persuade them to do so:

They're still in denial and because they're taking drugs they don't care. They don't even know if their babies are HIV-positive or no, they just won't listen to anybody.

She later acknowledged, however, that her own attempts to deny her diagnosis coincided with the period she was still using heroin.

I still knew all this time that I was HIV but I denied it to myself, denied it to myself til I came off drugs....

In R7's view, it would have been useless for her to have received any information or counselling for the first post-diagnosis years as she did not want to listen to it. She also continued to use heroin and other street drugs after her diagnosis, and this may also have been a factor in her early capacity not to think about her diagnosis. In her second interview she further related this strategy to the work involved looking after two young children. Her appreciation of this strategy was more positive however, than R12's, or that presented in the psychosocial literature:

I think sometimes that that gets you through..you know just getting on with it like and doing your everyday things.

R10 made a similar point. Asked when she had approached a certain organisation, she said she had been referred by a GP after giving birth to her son. Before then, she had tried to block out HIV. She explained that she did not have the energy or time to think about it as she was pregnant with complications arising out of another condition.

Several respondents' accounts of their initial reactions to their diagnosis indicated, therefore, that this had been a very difficult period for them, when loss, uncertainty and fear affected their self-concept. In response, many had tried to avoid incorporating HIV into their identity at this time. Some respondents now concurred with the psychosocial literature that this period of 'denial' was self-deluding and

unfruitful. At the time, however, as suggested by R7, it may have served as a protective mechanism which allowed them to deal with other priorities.

This finding might be interpreted as supporting Ciambone's conclusion, that other concerns may outweigh HIV infection, for example where chaotic drug use has been an issue. In my view, however, emphasising such priorities may have formed a way of initially coping with the diagnosis. Further, several of the respondents indicated they had found it harder to cope with the diagnosis more recently. The respondents' accounts do, however, highlight the relevance of Pierret's finding that some resources drawn on in the reconstruction of identity may already be in existence [1997]. In this study, this will be discussed in terms of emphasising continuity with the past as a resource in reconstructing identity. Over time, transformation may be emphasised to differing degrees and with reference to different aspects of the respondents' lives. This will be discussed further in the following sections.

Re-conceptualisations of Identity Over Time

Over time, most respondents found that ignoring their diagnosis became more difficult, and less constructive. They were therefore obliged to re-construct their identities in relation to HIV infection. In analysing the respondents' accounts, the literature on living with chronic illness again proved useful, providing suggestions as to the resources used by respondents in their post-diagnosis reconstruction of identity.

Literature On Living with Chronic Illness Over Time

As discussed, Bury [1982] also highlighted the reconstruction of identity over time. Carricaburu and Pierret [1995], Mathieson and Stam [1995] and Bartos and McDonald [2000] focus primarily on the differing degrees to which HIV infection or other illness is incorporated into the HIV-positive person's identity. Davies [1997] and Ezzy [2000] adopt a temporal approach, highlighting their respondents' conceptualisations of, and aspirations for, the future as key elements of identity reconstruction.

Several writers highlight the enduring concern of many people with chronic illnesses to continue as 'normal'. Davies interprets this concern as a refusal to relinquish a future orientation or to entertain any idea of the imminence of death [1997, 567]. Similarly, Ezzy associates this emphasis on 'living a normal life' with those who retain a conventional 'linear narrative' with respect to the future.

For Ezzy, this future-oriented self-concept is based on the assumption that the future can be controlled through human action, including medical science. He implicitly criticises those who retain this perspective as secular and self-centred, focused on preserving health and fulfilling 'material' aims, such as buying a house or having a child [2000, 610-11]. Ultimately, he interprets this type of self-perception as a doomed desire for continuity, which contrasts with the ability, developed by others, to celebrate spiritual and communal values and to accept death [2000, 613].

As mentioned, Carricaburu and Pierret interpret emphasis on continuity in biography more positively in their study of the effects of an HIV-positive diagnosis on 44 asymptomatic, haemophiliac and homosexual men in France [1995, 65]:

[they] did not reconstruct their life stories around their infection. On the contrary by questioning their pasts before the time of their infection, they re-arranged their lives so as to continue living as normally as possible [...] Biographical reinforcement [therefore involved] accentuating certain elements related to haemophilia or homosexuality of [their] previous identity [Pierret, 2000, 1595].

Carricaburu and Pierret's notion of 'biographical reinforcement' reflects the collective element of this source of identity:

[b]y relating the present situation to their reconstructed collective and individual pasts, interviewees could endow their present life with meaning. In this way, interviewees could try to find a new identity and continuity in their biographies [1995, 80].

The homosexual men in their study also benefited from support and information provided by gay community activism. As such they remained:

integrated in their affective environment and in 'society' [1995, 77-8].

Similarly, Bartos and McDonald highlighted a group of predominantly gay men among their respondents who prioritised their involvement in the gay, rather than, what they call, the 'HIV community' [2000, 302-4]. With some reservations relating to the 'middle class' domination of much gay activism, Small [1997, 16, 19] and Flowers et al. [1997, 93-4] also emphasise the importance of such resources to gay men.

These findings run counter to Ezzy's disassociation of communal values from any reconstruction of identity in terms of continuity with the past. It seemed to me, however, that such resources are unlikely to be immediately available to some groups affected by HIV infection, including women. As Gorna puts it:

one problem for most women with HIV is that they do not share in a community experience. When they meet other women with HIV they may have nothing in common but the virus [1996, 137; see Deren: 1993].

The Respondents' Post-Diagnosis Emphasis on Normality

Once again, this literature provided help with interpreting the transcripts. It is also worth emphasising the advantages of my use of biographical interview techniques here. The construction of chronologies, discussed with respondents during their second interviews, helped me to break down the broad brush of hindsight and to access events, subsequent to diagnosis, which influenced the respondents' reconstructions of identity, at various times, and with respect to different issues.

As a result of this analysis, the transcripts revealed that several respondents in this study also emphasised the importance of 'continuing as normal', albeit in different ways. While initially similar to their early reaction of not thinking about the diagnosis, over time this narrative incorporated an element of transformation. The respondents emphasised 'normality', but in spite of their diagnosis. As such, HIV infection is more present in this reconstruction of identity, in the sense of an element against which identity was constructed. For example, R4, R5, R8 and R10 emphasised the importance to them of living normally while not allowing HIV infection to dominate their sense of self.

Some respondents, like those interviewed by Carricaburu and Pierret, indicated that working was very important in 'continuing as normal'. For example, when R10 was asked if she had used a particular agency, she said she had not used it for herself but had accompanied her husband there. No-one had guessed she was HIV-positive:

because I was doing a normal job and going home to my family.

R4 and R5 also mentioned the importance post-diagnosis of having continued 'as normal' with their jobs.

For several respondents, including R12 and, to some extent R10, part of this emphasis on 'continuing as normal' related to their desire not to have to admit that they were different. Similarly:

[f]or most women, their construction of self is that of someone who is 'normal', mainstream and unremarkable. For such women, the process of disclosure is one with which they may be totally unfamiliar: stigma itself is likely to be an entirely new experience [Crawford et al.: 1997, 11].

In this light, R4, R5 and R10's emphasis on and pride in their normality might be understood as a form of 'biographical reinforcement' as normal mothers. Unlike Ezzy's wealthier respondents, most of these women live in communities where it is important to adhere to local norms. His characterisation of bringing up a child as an entirely individual pursuit would clash with the values of most respondents in this study. Furthermore, his advocacy of the acceptance of death would seem to reflect the perspective of a non-parent, a point which will be developed in the following chapter.

For some respondents, their strong emphasis on living normally in spite of their diagnoses contained a larger element of transformation, since they did not now consider their past to be 'normal'. R3's account, for example, suggests a level of pride in being able to comply with what might be described as mainstream or conventional expectations, after years of chaotic drug use and encounters with the criminal justice system. She described how after a year of being terrified, even agoraphobic, she had given herself:

a shake and started working in a pub and sortae, I think I pushed it to the back of my head when I worked [..]. You know I felt healthy and I was able to work and do what normal people done.

This was the advice she now gave to others:

just get up, live, ken, just carry on as normal, you know it's kind of difficult at timesbut if you do try and and carry on as normal as possible you'll be alright you know [...] just get on with your life and stop moaning.

Her emphasis on living normally, like that of other former drug users, represented the construction of a more reputable identity through a narrative emphasising discontinuity with the past. Unlike Carricaburu and Pierret's respondents, these respondents highlighted the normality of their current lives in opposition to the abnormality of their past lives, when they were taking drugs:

I think [HIV]'s probably opened my eyes a lot more into a lot of things [...] instead of sitting about taking drugs everyday and just being in your own wee world for the rest of my life (R7).

And it's been hard, it has been hard. Some days you're fed up and you think oh some smack would be lovely. [...] I had one time when I went on the street [...] and then I thought to myself this is stupid, you know I'm gonnae have to start stealing and it took me a long time to get the respect from my family back and [...] to be able to walk by these drug dealers and everything [...] but I had to do it for my daughter (R12).

Many respondents therefore emphasised the normality of their lives post-diagnosis. In some cases this reflected a desire to highlight continuity with their life pre-diagnosis, in spite of their HIV infection; in others, a wish to underline a much greater post-diagnosis transformation. All of these respondents had, however, pointed to their 'normality' in order to assert a reputable identity. In the light of the stigma and uncertainty attached a diagnosis as HIV-positive, particularly when many of the respondents were diagnosed in the 1980s, the self-affirming, positive nature of this construction of identity may be appreciated. In the next section, the impact of various threats to maintaining this narrative of identity over time, will be discussed.

Managing a Narrative of Living Normally In Spite of HIV Over Time

Mathieson and Stam point out that living with such a chronic diagnosis requires:

continual readjustment[s] of identity [1995, 186].

Carricaburu and Pierret also suggest that it may be more difficult to maintain a narrative of living a normal life in spite of the diagnosis once a person becomes symptomatic [Pierret: 2000, 85]. The relevance of these points to interpretation of the transcripts was also suggested in relation to other issues and events which presented threats to this narrative at various times.

R1, who, unusually, had previously held relatively well-paid jobs, felt undermined by her inability to work. Although presented as a long-term response to HIV-infection, her vehemence was likely the result of the recent breakdown in her social support, a subject which dominated her interview:

I haven't worked for several years. It's pretty bizarre actually as I've worked all my life [...]. It's so strange not having regular employment, even part-time [...]and before I knew it, I was moving house and my health went downhill. [...] so that kind of screwed up my job and since then I've been wary of starting work because I can't tell from one week to the next whether I'll be OK, one day to the next, [...]...bizarre...the insecurity of not knowing whether you're going to be normal in a week's time, in a month's time, it's just bizarre, it really is bizarre....[Further] [i]t would be nice to have a job and be normal, but my health just doesn't permit it.

This impassioned response to my very broad-brush question, as to what had changed for her since her diagnosis, underlined how her current feeling of not being normal was a barrier to her reconstruction of a self-affirming identity. Although this had not always been the case, at the time of her interview she felt overwhelmed by her diagnosis and its consequences:

A normal 40 year old would have a pretty regular job, car, mortgage, insurance and I can't have any of these things [...]. I mean nothing has been normal for the last 11 years. Although I've had to try and be normal for the kids [...] Nothing is, nothing's normal..[...] Absolutely everything is changed and I can't think of

anything that isn't affected by how you feel, how your health is and not knowing...[....] it's the uncertainty of it that you feel....[.] really at odds with the rest of the world. It's bizarre.

Another example of events difficult to reconcile with a narrative of living a normal life is provided by R10. While discussing her time-line, she indicated that there had been previous periods when it had been impossible for her to consider her life as 'normal'. In particular, for the period around her partner's illness and subsequent death, HIV had come to dominate her identity:

[it was like that] my life all it consisted of at the time...just HIV and AIDS..I mean for about two years before he'd been ill before he died.

Since then, she had worked to reduce this dominance of HIV infection, but accepted that the diagnosis was now more 'real' to her, that she was more emotional about it, and that:

in the last couple of years, definitely, my whole attitude on HIV's just changed completely.

In a throwaway comment, she suggested that she could not entirely assimilate her current life into a narrative of normality, although that narrative was still important to her:

I think....my life's never boring! Sometimes I wish it was (Yes?) Aye, normal 9-5 job all day and a husband at home and a kid. That would be fine.

R3 also discussed events which she found difficult to assimilate into a narrative of normality. Some of these events related, as Carricaburu and Pierret suggest, to HIV-related illness in herself or others. It is interesting, however, that R3 had also found it difficult to accept any re-classification of HIV infection as a chronic, rather than a terminal, illness:

the doctor says 'but you're not terminally ill'. I says 'but you were the one who told me that I was [..]. Make up your mind! One minute I am [and then] because I'm on this therapy, I'm no'. But naebody knows how the combination therapy is going to work.

She resented this re-classification despite its positive implications in terms of her health, a reaction also observed in other women by a service provider whom I interviewed. R3's strong reaction highlights the threat of this development to the identity she had constructed, for over a decade, as a person living normally *in spite of* a terminal diagnosis. This new information had the potential to remove part of the basis of this narrative, a prospect she found disorientating.

R1's, R10's and R3's accounts provide examples of events and information which, at times, they found difficult to assimilate into a narrative of normality, to which they continued, where possible, to subscribe. The following section, however, provides examples of reconstructions of identity incorporating HIV infection to a greater extent. Some respondents recounted how they had come to view HIV infection as a positive event, transforming their self-perception. At least with respect to certain aspects of their lives, these respondents had moved from a narrative emphasizing normality in spite of HIV infection, to one which incorporated HIV infection into their lives in a positive way.

Reconstructions of Identity Incorporating HIV Infection

In their articles, Mathieson and Stam highlight a need to:

incorporate the illness experience into the narrative [1995, 301].

This may be reflected in R6's response to my general question as to what had changed for her since diagnosis. She emphasised that it had taken her a long time, with the benefit of counselling, to reduce the dominance of HIV infection over her identity:

I could write a book....you go through different phases with the diagnosis [...] different varieties of the denial bit and it comes to a point where you cannot deny it any more.....and then then you go through, like, the why me and all that and feeling sorry for yourself [..], walking about feeling like who to tell, what to do about all that and feeling like you're a walking virus, and you have to go through all that different stages until you get to the point where..I'm not saying everybody does it but, ehm....and I found it hard, [...] I've done all that ehm but it's helped me be through to what maybe I am today [...] all the...sort of mental trauma with HIV,

[..] but now I'm veryvery ehm I suppose content, I'm not like 100% brilliant ...and that, but it's taken a long time, a long time to actually accept it in myself.

Her account emphasised how her initial denial of her infection and feelings of contamination had been replaced by a self-perception which incorporated HIV, but did not let it dominate:

I'm not like Mrs. HIV, but it's one aspect out of like 1000 other different aspects of me [...] I don't pretend anymore.

It was evident that this reconstruction of identity had been very difficult, but gave her a great sense of satisfaction. Her pleasure at being able to advise other women with HIV infection illustrated her sense of having escaped a previously negative self-perception:

[it's like] being on the other side of the walls.

Her comments recall Mathieson and Stam's finding that:

Cancer survivors in the study often reported a sense that they had reached a point where 'cancer no longer encircles' their lives [1995, 299-301]

They also observed that respondents often spoke positively of dichotomies between their lives before and after cancer. Some respondents in this study made similar remarks, emphasising how they had become more self-confident, focused and capable through coping with their diagnosis:

I think I'm a lot stronger as a person [...] than what I was before [...] I think I cope with things better [...] I try to solve things a bit quicker, that normally I would put off and off (R4).

Life's been more important and bringing my kids up has been more important to me since then (R8).

Some of the respondents' accounts came close to the 'epiphanies' reported by Stevens and Tighe-Doerr [1997, 528]. R7 mentioned getting involved in art, an opportunity she also felt she would not have had prior to her diagnosis. Similarly:

I've more or less found myself I would say ... Oh aye, it's a positive thing for me..
Really positive like I've always written poems but I think if I wasnae positive my
poems would never have been published (R3).

The Effects of These Long-Term Processes of Identity Reconstruction on Service Use

The respondents' accounts indicate, therefore, how diagnosis constituted a major 'biographical disruption', requiring them to engage in a process of re-negotiation of identity. The resulting narratives of identity performed an important self-affirming and protective role. However, it was also the case that these narratives were sometimes threatened by events such as illness, bereavement, and the loss of social support. At the same time, some respondents had developed more positive self-perceptions with respect to certain aspects of their lives since their diagnosis.

As discussed, the sociological literature on living with chronic illness proved very useful in analysing the transcripts. In general, however, this literature did not include service use in its analysis. Further, the literature on HIV services tended to assume that once an 'objective' need had been identified, a service only had to be provided, and well publicised, for it to be used. Analysis of the respondents' interviews suggested that questions of service use and of need should be approached from the perspective of potential service users, taking account of the issues discussed in the first part of this chapter. Some assistance with this analysis was provided by work on lay conceptions of health and illness and the social significance of using primarily medical services [Blaxter and Paterson: 1982; Cornwell: 1984].

Early Post-Diagnosis Attitudes To Service Use

The first part of this chapter indicated that the initial post-diagnosis period was very difficult for most respondents. Many recounted feelings of being stigmatised and 'contaminated' by their diagnosis. At this time, the respondents report little service use, in spite of receiving a potentially terminal diagnosis. Most, but not all, used medical services, but attended for basic check-ups only. In this section, the relationship between the respondents' early post-diagnosis self-perceptions, and their lack of service use, will be discussed.

Analysis of the transcripts strongly suggested the contribution of the respondents' early encounters with medical services to their negative self-perceptions. For most respondents, their first use of any kind of HIV service was at diagnosis. Several authors have emphasised the importance of this initial encounter, and of the subsequent relationship between doctor and patient, in moulding the self-perception of the chronically ill person, particularly where the patient is socially isolated [Charmaz: 1983, 180; Roth and Nelson: 1997, 162].

Roth and Nelson found that diagnosis with HIV infection was often handled in an 'impersonal and routine' way:

leaving many patients at a loss as to how to adapt to such a drastic change in their self-perceptions and their relationships with others [1997, 161; also see, more generally, Mathieson and Stam: 1995, 298-9].

These conclusions seem overly tentative in light of these respondents' accounts of their experiences of diagnosis, many of which took place in the mid-1980s, at the height of concern about HIV infection, and at a time when the diagnosis was considered terminal. 'Impersonal and routine' hardly describe the brutal way in which several respondents were treated by medical staff. Respondents were in no doubt that these experiences had reinforced their negative self-perceptions on diagnosis, making them less likely to consult HIV medical or social services subsequently.

R7's experience of diagnosis was particularly brutal and worth relating in detail:

I was 7 month pregnant [...] I had a cyst on my womb and they were gonnae remove it before I went into labour [...]. And I remember going in [to hospital] [...] and I says my name's.....and I'm here forand this sister had a heart attack, really she just went 'get out' [...]. I ended up getting flung out the [hospital] they wouldnae take me.... this was me just finding out and naebody had told me ... And this woman was like 'you're not getting in my theatre. If I put you in my theatre I'll have to close it down and I'll have to scrub it'[...]She was going on about and I was like 'what are you talking about?' And she went, [...] 'you've got

AIDS'... and honestly I was 7 month pregnant and I was like..and there was all these people sitting waiting. Well I mean, and she's told everybody.

She later realised that her GP had known of her infection previously, but had not told her, as she had been tested without her consent. He had withheld this information even though he knew she wanted to start a family.

Several other respondents were also tested without their consent. R1, for example, was handed her folder by a receptionist, and told to take it with her to the ante-natal clinic when she arrived for a check-up six weeks before her due date. To it was stapled:

a green and white computer paper list: Hep A negative, Hep B negative....HTLV-3 positive. And I went 'oh my God, that's the thing they're all dying of in America' [...]and this was while sitting in a room full of pregnant women waiting to be weighed and samples taken...and I'd no idea I had it, no idea I'd even been tested for it.

R6 commented directly on the effect of the attitudes of medical staff on her self-perception. Asked in the first interview about things or circumstances that she found difficult, she responded:

....other people's attitudes probably, that's about the best thing I could say that's been difficult to cope with ...[Can you think of examples of that?] Ehm...[...] the medical staff played a big part in how I felt in my whole being regarding HIV...[...] their total negative reaction, which was a bit sad because, you know you feel that they're right....[...] played a big part you know [...]...and it came from an area where I least expected it would.

Access to specialised facilities was more difficult for R9 than other respondents, since she lived outside Edinburgh. Her experience of diagnosis had, however, played an important role in her non-use of any medical or social HIV service, for nine years post-diagnosis:

I was asked to go for a short discussion when I was pregnant [...] and he told me that I had been tested for HIV and I was positive. [...] And I was advised to have a termination and this was all in 10, 15 minutes. And then I was asked if I wanted a

cup of tea and took back to the waiting room [....] So after, I had a termination and I wasI'd always been pro-life....so it really done my head in.

Having an abortion at a very late stage of her pregnancy had distressed her greatly, and she found it very difficult to talk about this in the interview.

R2, R3, R8 and R12 also recounted insensitive handling of their diagnoses by Edinburgh and Glasgow GPs and hospital doctors. Several respondents (R1, R6, R7, R9 and R12) were pregnant at the time of their diagnoses, and felt that medical staff strongly disapproved, an issue examined further in the next chapter. R5 was very critical of a dentist who had loudly refused to operate on her, breaching her confidentiality in front of a room full of students. R2 also related several instances of insensitivity on the part of her former GP.

In the initial period post-diagnosis, therefore, many respondents' feelings of contamination by the virus, or 'bodily disruption', were reinforced by their encounters with the medical profession. Although recounted years after the event, the emotion underlying these accounts was palpable. In this light, non-use of services might be perceived as a strategy of self-preservation.

Several respondents had felt stigmatised, not only by their encounters with medical staff, but also by any association with the City Hospital itself. A GP with considerable experience of treating HIV-positive patients emphasised how hard he found it to persuade some young women to use the City Hospital because of its association with drug users. Similarly, R10 related that she had not wanted to go there at first because:

I didn't want to go and sit beside all those drug users and people knowing that I was HIV.

R7 also commented that she had felt pushed into using the City Hospital rather than the GUM clinic, which was the first specialised service she had attended:

I thought that what they were trying to do was like they were trying to keep all the drug addicts and that to the City [....] and I felt like the gay scene and that they all

went to the Infirmary [...] And it's still like that.. you dinnae catch the gay men and that going to the City.

Non-use of services at this stage also reflects 'denial' of the diagnosis, in order to avoid being overwhelmed by its potential implications. Non-use of medical services was reported by one of Huby et al's respondents in their study of the use of medical services in Edinburgh:

I hate going to the hospital. Because it brings everything back to reality. You realise you have HIV. You are going to die, ken, all that comes flooding into your head when you go to the hospital [1995, 61].

R11 gave a similar explanation for her early non-use of the City Hospital:

because you were given no information [...]and you thought that all it meant was death, and I remember the first time I went to the hospital, I was just sitting there and it used to be horrible [...]at the City before they moved to the new ward. It was dark and it was dingy, minging... and I remember just looking round and seeing this person beside me who was really quite ill, and it just frightened the living daylight out of me and that was the last time I went for oh 2 years.

Huby et al's respondents' doctors viewed this strategy as problematic [1995, 65]. Like Chidwick and Borrill [1996, 274], however, these authors concluded that:

apparent denial of a terminal prognosis and avoidance of its consequences is often part of the process of coming to terms with death. What may appear as denial to some service providers may hide full knowledge of the situation and a well reflected strategy of coping [1995, 61].

For the respondents in this study, denial seemed to provide a self-protective response to brutal experiences of diagnosis, and the difficulty of accepting a stigmatising, potentially terminal diagnosis. Minimising service use seemed to be part of this denial, resulting in the non-use of any HIV-specific social services, and little or no use of medical services. In the next section I will discuss service use in light of evolving narratives of living a normal life in spite of the diagnosis.

Fitting Service Use Into a Narrative of Living a Normal Life

In the first part of this chapter, I discussed how respondents had spoken of pushing HIV infection to the back of their minds, and subsequently of living normally in spite of their diagnosis. In terms of service use, these narratives were associated with very different initial perceptions of medical and social services.

Most respondents' use of specialised HIV medical facilities in Edinburgh and Glasgow,¹ fairly soon after their diagnosis, may be explained in part by their pregnancies or use of substitute prescription. First interview questions as to whether medical or social services were easier to approach, however, revealed marked differences in attitude to different types of service. In particular, respondents were far more reluctant to approach social services, whether in the statutory or voluntary sectors. The respondents' time-lines compiled from their first interviews, and checked with them in their second, revealed that no respondents had used social services during this initial period. In fact the average period before the respondents started to use social services was six years, and the periods of non-use ranged between one and 11 years post-diagnosis. It seemed that social services were much more difficult to reconcile with a narrative of living a normal life.

At first sight, the use of medical services regularly monitoring blood counts would also seem incompatible with the narratives of pushing the diagnosis to the back of one's mind, or of living 'normally' in spite of the diagnosis. As discussed, however, the latter version of this narrative in particular, does allow for some level of recognition of the diagnosis. Asked whether she had put the diagnosis to the back of her mind at any period R10 responded:

I did that for the first couple of years really. [...] I used to go to the City for check ups but I used to just go, get bloods taken, go away and never ever questioned anything. Like my blood counts whatever, I never ever questioned it. Went and that was it. I always worked full-time so I had that one to keep me going.

¹ In Edinburgh this was the City Hospital and is now the Western General Hospital and in Glasgow the Ruchill Hospital (now moved to the Gartnavel Hospital).

This distinction in perceptions of medical as against social services, and the complex relationship between perceptions of normality and use of these services, is discussed in the work of Blaxter and Paterson [1982] on the use of health services by lower-income women in Aberdeen, and Cornwell [1984] on lay conceptions of health and illness in East London. Both studies found that health was considered a moral issue [1982, 124; 1984, 122]. Cornwell explained that illness was seen by her respondents as something that interrupts the normal [1984, 124]. Her respondents often insisted they were healthy, despite having quite serious medical conditions. Blaxter and Paterson's found that:

[m]inor illness could be ignored, and chronic complaints defined as normal if they did not prevent ordinary functioning [1982, 34].

Several other researchers in the United States and Britain have also found that the chronically ill are unlikely to get much support or sympathy, unless diagnosed with a recognised, and therefore legitimate, medical condition. They suggest that many people are unlikely to seek help unless diagnosed with such a condition [Charmaz: 1983, 184; Bury: 1982, 70]. The morally correct position therefore is to 'get on with it', and not to moan.

These findings are helpful in interpreting the respondents' early attempts to reconcile service use with living 'normally'. They did not completely ignore their terminal diagnoses, and did use medical services. However, they could approximate the morally correct position identified, by getting on with it, not moaning, and not using too many social services. In this context, their narrative of identity might be seen as living as normally as possible in spite of their diagnosis. The importance of this narrative may be reinforced by the respondents' concern to maintain confidentiality.

Cornwell's work is also useful in predicting the extent to which different types of service use may be assimilable into this version of normality. She found that her respondents tended to hold a strict hierarchy of the respect due to different types of service providers. They were more respectful of hospital doctors than of GPs, and of GPs than of maternity or community health workers [1984, 175]. Services provided

by the latter with respect to pregnancy were resented by her respondents. They were also hostile to social workers whose expertise was denied:

common sense was said to be what was required to deal with the ordinary problems of everyday life such as those that they see tackled by social workers [...] [while] medical knowledge and medical skills were said to be appropriate to problems that ordinary people cannot cope with [1984, 182].

Several respondents in this study provided similar explanations. Asked why she was able to use specialised medical services six years before she contacted any social service agency, R7 responded:

I think because you [...] think well they're doing their job [...] whether it's doctors or you're in hospital and it's nurses whatever [...]. I used to think it was [...] that's the only point of them wanting to become a doctor or a nurse is to help people [...]. I just really felt I really really didn't know what to expectthe first time I came in here (social agency) whereas the doctors, you just went in and you weren't bothered what they thought of you.

By implication, she also suggested that use of medical services did not imply any moral lack in her.

Another respondent, who also did not use social services for several years after diagnosis provided the following explanation, resonant of Cornwell's findings on the respect accorded the medical profession, particularly specialists. Asked why it was easier to use medical services rather than HIV-specific social services, she said:

because I thought well they're doctors and consultants and they all know what they're talking about (R2).

While use of medical services was considered compatible with this narrative of living normally, use of social services in the statutory or voluntary sectors was not. In short, early versions of this narrative, at least, did not afford the respondents a 'legitimate' need for using social services, which might be considered more akin to moaning.

In the following sections, the respondents' comments as to the reasons why they found it difficult to use certain social services and treatments,² and why they sometimes had started to use them, will be examined in terms of the narratives of identity previously discussed.

The Difficulties of Assimilating Social Service Use Into a Narrative of Normality

Over the years, the respondents had come to use social services. It was clear, however, that this development was often very difficult, involving an evolution in the respondents' conceptions of what constituted living a 'normal' life in spite of their diagnosis.

In the first interviews, I asked the very general (if with hindsight, loaded, question): 'do you find it difficult to ask for help?', in the context of others relating to housework, shopping, looking after children and emotional support. The responses were vehement and strikingly similar, as indicated by my use of italics, and reflected Cornwell's observation that getting on with it includes completing expected duties:

Oh...I do aye because I'm very *independent*...I tend to seek the help for myselfI find out [..]how I can go about it myself rather than go to someone else and asking them to help me. [...]stubborn I suppose (R3);

Aye.... I'm one of they people aye, too *independent* (laughs). [Why?] I dunno I've just been like that all my days I think. Just...one of they types (R8);

It is for me because I've always been such an *independent* body and I've always been the one who that managed, coped and dealt with the budget, with the bills (R1);

So I've just been very *independent* since [the death of her husband] so I find it really difficult to ask anyone to do anything for me...' Further, 'Umm.....I'm very difficult to cope with if I need to ask for help or I need help in any way. I just really hope that someone will recognise that there's something the matter (R2).

² The use of statutory social work services will be discussed in the next chapter on identity and motherhood.

Similar comments were made by other respondents, including R11, who associated asking for help with whingeing, and R6, who equated asking for help with weakness:

I suppose in general I'm classified as quite strong in that way although you know sometimeswell everybody's got their weaknesses, eh, all got our bad days...

Even more strongly, R12 associated asking for help with begging:

At first I would have been embarrassed aye because it makes you feel low that you're asking for something, that you're begging [...] so you just tell yourself that I'm no gonnae ask, I cannae ask.

Although most respondents expressed their desire for 'independence' as an individual characteristic, the uniformity of these answers pointed to a strongly-held norm. There was a strong association in their minds between receiving certain types of (social) help and not being independent, not being normal. Asking for such help was still not felt to be a legitimate thing to do, in certain spheres.

Their remarks strongly recalled Cornwell's findings above. By the time of their interviews, however, most respondents were in fact using some sort of social service. Since most of the respondents still emphasised a narrative of living normally, in spite of their diagnosis, this indicated an evolution in their conception of 'normality', and a process of overcoming fears with respect to entering uncharted waters.

R9 provided several explanations for her long-term non-use of social services:

You can only take in so much at a time. You have so much to take in when you're newly diagnosed and you're in shock [...] it's a long process.

I know there's people out there who are positive and they won't use services anywhere. [Why?] For fear of being recognised, fear of their diagnosis being right, fear of disempowerment. Lots of things.[...]It's facing your fears isn't it, it's facing the unknown.... you don't know anyone, you don't know about HIV, you don't know what to expect.

She therefore associated use of social services with learning about HIV infection, in a way that use of medical services was not. Similarly, despite her use of the City

Hospital, R7 explained that she had not contacted any social services for six years after diagnosis because she was:

trying to hide and forget. And embarrassed

Her initial response as to a question as to how she would advise a newly diagnosed woman with respect to social services was to emphasise the importance of information. On reflection however, she revised this:

but.....I feel like it's nothing even anything to do with [information]... it's really in yourself, whether you've got to the stage when you want to go and tell people that you've got the virus or you want to get involved with organisations.

R8 emphasised her fear of the implications of disclosure. Asked to explain why some mothers she knew had decided not to use social services she said:

Oh, they're just scared, they just dinnae want to beknown.....I think well yes to *come out* I suppose (To come out?) Yes.

R10 made a similar point. In her view, confidentiality protected a woman from having to think about her diagnosis. In her experience, once other people knew about the diagnosis it became much more difficult to ignore it.

Confidentiality had, therefore, been an issue for all of these women in deciding whether to contact social services. Analyses of confidentiality generally emphasise fear of being stigmatised by others as the major concern. However, these respondents also reflected on their fear of associating themselves publicly with HIV infection in case it meant they would not be able to return to ignoring, or to a lesser level of recognition of, the diagnosis.

Other comments highlighted respondents' fears relating to the manner in which their requests for help might be received:

so I think you learn how to do everything for yourself, [...] rather than having to face the rejection of somebody saying bugger off or I cannae help you (R3).

I always have been like that as well, that's just...ehm....a fear of rejection thing
[...]I'd rather just stick it out and whatever than..I don't ask for help...(R6).

These points suggest a fear that their requests for help might be turned down, and that their own perceived needs might not be viewed as legitimate by others. The concern not to be seen as 'whingers' or 'moaners', asking for help when others might need it more, would also seem relevant here. This view is supported by several respondents' comments that they preferred to wait for others to pick up on the fact that they might need something, thereby legitimising that need, rather than asking for it themselves.

Further Barriers to Reconciling The Use of Certain Services and Treatments With a 'Normal Life'

The use of non-medical services in general was therefore made more difficult by most respondents' strongly-held aspirations to live their lives 'normally'. The points made above indicate the difficulties associated with re-negotiating their conception of the level and type of service use compatible with living a 'normal' life.

These difficulties were accentuated with respect to the use of certain social services and medical treatments. Often these remarks suggested a fear that the use of such services could only mean that they had somehow given up on a normal life, or that their HIV infection had progressed, or that they had stopped resisting its progression. Ultimately they also highlighted the respondents' awareness of the importance, but also the difficulty, of maintaining a narrative of living a normal life, since the use of services had to be re-negotiated on an individual basis.

In the first interview, several respondents reacted strongly to suggestions that they might use a homehelp. R3's response to this question was:

the day I get a homehelp is the day I give up.

In the light of these responses, I decided to put R3's comment to all of the second interview respondents, some of whom maintained their strong opposition to this service.

R8 indicated that she would not allow any services to come into her home. R2 also mentioned this concern, but emphasised her particular reluctance to allow anyone else to do the housework:

I'm stubborn, I'm my own worst enemy. I'll no stop because I'm feared as I said to you to stop. It takes me until I'm collapsed to lie down so I can understand what the woman was saying to you about the homehelp. They'll be no homehelp coming in my house.

R2's response recalled Cornwell's findings on the moral nature of health. She concluded that perceptions of health further related to the capacity to work and to fulfil one's, gender-determined, role:

[i]n general the requirement of women is that they should be seen to run their homes properly [and] [t]he need to show that one is at all times ready and willing to work affects the way in which they think and talk about illness [1984, 71].

The importance of the home was magnified by the fact that, as in this study, most of her women respondents were not working. She found that they would try to accommodate their symptoms of ill-health by cutting out certain activities and slowing down:

anything in order not to have to give up altogether which would mean that there would be no-one to look after the children and no-one [...] to look after the women either [1984, 140-1].

R3 also clarified her concerns with respect to using a homehelp:

I could do with a homehelp, it's quite a big house to clean, [...] I suppose it's the same sortae idea of going on combination therapy. The day you go on that is the day you're admitting that there is something worse than what there was before ...you have to take this in order to survive. And having a homehelp would be like similar by the fact that well I cannae do this for myself... in the long run you know, eh, so obviously it gives you recognition of your illness and how far it's progressed. So I wouldnae want to be reminded of that.

She therefore did not consider homehelps as merely a service with the potential to remove some stress from her life or help her to conserve energy. Instead, this service was associated with the progression of HIV infection, and the commensurate removal of her independence and sense of normality. Similar concerns with respect to accepting a homehelp were also mentioned by several other respondents, whose attempts to re-negotiate these meanings will be discussed below.

Several other services had not been used by respondents because of the association, in their minds, between use of these services and the progression of HIV infection. Despite her worries about over-treatment by doctors, and attachment to the value of self-determination, R3 had recoiled from making a living will:

I feel that's something you would do when you were ready to go and [...] I'm terrified.

R11 had steered clear of using the City Hospital for some time after her diagnosis, partly because she was upset by seeing people who were seriously ill. Initially, she had also refused to use a residential respite facility as she thought it was only intended for people who were dying. She had eventually decided to use this facility but dreaded seeing candles lit there for people who had died over night. Seeing this still gave her the:

urge to run away and take up a new identity and just pretend that I'm no ...but how can you get away from it?.

R2 had maintained her refusal to use this same facility for similar reasons:

I'm too feared of it. That's the truth. [You're afraid of it?] Afraid to lie down and stop for a long period of time.

R4 had only been to a women's support group at Solas once. She had never returned as the obvious illness of the woman sat next to her had distressed her. At the time of her second interview, she was also trying to decide whether or not to try a combination therapy. The difficulty of making this particular decision was also emphasised by R3, R10 and R11, who also associated these therapies with progression of HIV infection and consequent loss of normality.

At the start of this interview, without my having asked a question, R4 spoke for a substantial period about this decision. It was a subject to which she returned again and again during the interview. Part of her difficulty related to her association of combination therapies with the progression of HIV. In part, however, like R3 above, she had difficulty with the possibility that combination therapy might provide hope of long-term survival. Previously, she had adopted a fatalistic approach. As she explained:

when your time's up, your time's up and I've learnt that over the years [...] when my brother just died, that was it. There was no warning.

Making the decision to start combination therapy would therefore require her to re-negotiate her basic approach to the significance of living with the virus, a process she was finding very difficult.

Examples of Attempts to Re-Negotiate the Meanings of Particular Services

The difficulties involved in re-negotiating the meanings of certain services, particularly in light of the narrative of getting on with a normal life, were therefore evident in the transcripts of several respondents. At the time of the interviews, certain services were regarded as out of bounds, situated beyond personal lines drawn in the sand.

However, the transcripts contained several examples of re-negotiations, or at least partial re-negotiations, of the meanings of particular services, allowing the respondent to use them, while maintaining a narrative of living normally in spite of their diagnosis.

R3 provided an example of how she had overcome her fear of certain services but not others. Her comparison of the decision to use a homehelp service to the decision to start using combination therapies is cited above. While she continued to reject the idea of the former, she was however taking a combination therapy at the time of both interviews. This discrepancy further emphasised that the meanings of services needed to be re-negotiated on an individual basis, and that moving towards greater service use was unlikely to be a smooth process.

In response to my second interview question, R10 and R12 both indicated that they would accept homehelp services, if necessary. At the time of her interview, R12 was about to be discharged from hospital after a serious AIDS-related illness, and was to receive help from a variety of social services. She was very happy that these services were to be provided. However, she was also careful to emphasise that she had gone through a long period of not using these services, despite illness, before arriving at this point, and that she had been embarrassed to ask for help. Further, with reference to her continued refusal of a place in a respite care facility, she quickly returned to the 'because I'm independent' explanation.

R10 explained her change of attitude to taking on a homehelp in similar terms. When asked to respond to R3's comment she replied:

No, I've come to the conclusion that if I need a homehelp I'll ask for one. I've decided I'm no gonnae be silly and try to get on with things when I'm not able to. [...] See my Hoover's just lying there and my toilet..I've half cleaned it and I'm a bit like that the now, I've been like that for a while. [...] It's just I find it quite ...tiring at times. But no, I would ask for help if I needed it.

Her comments still indicate a conviction that to be legitimate, a need must be quite pronounced and only recognised as such after great difficulty. For example, she related her new attitude to her experience of coping on her own while caring for her dying husband. At that time she had refused offers of help:

I was like oh I can get on with thisoh no no no I'll be fine.

While recognising their physical need for help, these respondents still felt it necessary, therefore, to justify their present use or attitude towards services with reference to past experiences of having tried to deal with the situation on their own, and having suffered for that decision.

R11 had agreed to take a homehelp between her two interviews. Her account of this decision emphasised the role played by her community worker in persuading her to accept this service. Again, pointing this out may be a way of legitimating her need. Her continuing ambivalence with respect to this service was evident, however,

illustrated by her account of how she insisted on helping the homehelp with her job. Similarly, R8 recounted that she found it very 'awkward' to tell someone where to clean. A social worker also told me that one of her HIV-positive clients had stopped using homehelps as she had found herself cleaning the house before the homehelp arrived.

These accounts resonate with Cornwell's findings on the importance to her female respondents of being able to look after their homes. They also suggest that despite having recognised a greater level of need, these respondents found it difficult to integrate the use of homehelps into their narrative of normality.

R4 understood the other respondents' difficulties with the issue of homehelps and why some respondents refused this service:

I think a homehelp it is a hard decision because you think well if I can't do this what's the point of being here?

When asked whether she agreed with T3's comments on the significance of housework, however, she commented:

No I wouldnae. [...]Years ago I would have said the same but I think [...] it can work both ways right. Getting a homehelp, right it can be admitting that you're not well, but it can also be a way of saying look I'm not able to do that but I'm not gonnae give up, therefore I need help. Sometimes it's really hard to ask for help. Especially in cleaning your own house. [...] But I do understand that cos I said the same myself years ago. But [...] it can really beneficial you know in the sense that you're not accepting the homehelp because you're giving up, you're getting a homehelp to improve your standard of living.

R4's reconstruction of the meaning of having a homehelp did therefore allow for an admission of a greater need for help from others, while also emphasising that accepting this service did not signify giving in to the virus. She had therefore constructed a narrative which, at least with respect to homehelps, did not associate a greater acceptance of the effects of HIV infection with a less reputable, or less normal, identity.

The interviews also indicated that, some years after their diagnosis, several respondents had started to use HIV social services, such as Solas and Body Positive Edinburgh and Glasgow, which provide meeting places for people with HIV infection. Use of these services was often discussed by respondents in terms of self-determination or empowerment, as will be discussed later in this thesis. However, it also implied a greater incorporation of HIV into their identity as hinted at by R10's comments above, and my construction of time-lines according to which several respondents' use of these services followed a bereavement.

Several respondents recognised that they had drawn on these services in their reconstruction of a positive post-diagnosis identity. R12, for example, recommended the use of one such agency as:

reassuring...you learn to like yourself again because you're no that different.

Similarly, R3 would advise HIV-positive women to come to the self-help agency with which she is involved because through it they could learn:

you're not alone.. And if you come to BP or Solas you'll meet people like that and you'll feel better about yourself.

R7 and R11's comments went further, suggesting that in some ways involvement in services, and in R11's case, activism, had improved their lives as compared with before their diagnoses:

I started doing things [...] to try to do things with my life and it's really been [agency] that have kind of got me there to tell the truth. Last year [...] I had work in a gallery [...] and I was meeting photographers from America (R7).

R11 reflected that as a woman who was open about her diagnosis she had had opportunities she would not otherwise have had. She had travelled a little and met a lot of people:

It's opened up wee horizons for me.

R2, R3, and R9 were particularly enthusiastic about their involvement in HIV self-help groups. As such, they may be among those for whom HIV represents a 'career'

[Bartos and McDonald: 2000: 302-4]. These writers argue that the respondents in their study whom they classified in this way distinguished any involvement in HIV organisations from their sense of self. In my opinion, however, any level of commitment to a career, cannot be separated from a person's self-perception or identity, and this constitutes a further element of the post-diagnosis reconstruction of identity which will be analysed later in this thesis.

Conclusion

Analysis of the interviews provided strong evidence of the type of 'biographical work' identified by Bury and others as an important response to the disruption caused by diagnosis with a chronic illness.

Initially, respondents had often denied their diagnoses. This denial had served as a protective measure against the brutality of diagnosis, discriminatory attitudes of medical professionals, and fear of potential death. Potentially fewer resources for identity reconstruction were available to women than to some men with a history of activism around an aspect of their identity. The respondents had, however, engaged in a difficult process of reconstruction of identity, drawing on elements of continuity and transformation. Most had constructed an identity of living normally in spite of their diagnosis, which implicitly recognised the reality of being HIV-positive. Some respondents had incorporated HIV into their identity to a greater extent, crediting it with positive developments with respect to certain aspects of their lives.

Some of these interpretations of the interviews were assisted by the rich sociological literature on living with chronic illness. This literature provided little help with respect to the potential influence of such reconstructions of identity on different types of service use, however. More useful in this regard was literature on lay perceptions of health and service use. The methods used in this study, including the construction of time-lines, were also very helpful in gaining an understanding of how processes of identity reconstruction, and different threats to the maintenance of narratives of identity, had influenced service use over time.

These narratives were therefore an important influence on the respondents' attitudes towards, and use of, different social services and medical treatments. Where a particular service could not be fitted into a respondents' current view of the way they were leading their life, it would not generally be used. In general, the respondents were far more reticent with respect to using social, as opposed to basic medical, services. Social service use was perceived to conflict with their post-diagnosis identity of continuing to live normal, independent lives. Over time, however, the transcripts also provided examples of ways in which respondents had re-negotiated the meanings of particular services to present less of a threat to their post-diagnosis identity, thereby expanding the level and type of service use compatible with a narrative of living a normal life in spite of their diagnosis. The enduring importance of continuing as normal could be seen, however, in the attention paid to justifying these shifts, and the fact that no respondent reported a wholesale change of view.

This chapter has examined the respondents' reconstruction of identity with respect to their diagnosis itself. In the next chapter, I will look at another important influence on respondents' post-diagnosis identities, and consequently their service use: their status as mothers.

Chapter 5: The Good Mother: Constructing and Sustaining a Post-Diagnosis Moral Identity

In the previous chapter, I discussed the respondents' reconstruction of identity in light of their HIV-positive diagnosis, and its effects on service use over time. Initially, most respondents had tried to resist any acknowledgement of their condition, emphasising the importance of living a 'normal' life. This insistence on 'normality' was often retained over the years, but gradually evolved to incorporate a greater recognition of their HIV infection. This analysis led to me to explore the potential resources on which the respondents might further draw in their post-diagnosis reconstruction of identity, such as community involvement, work, intimate relationships and motherhood. The latter three are examined in this chapter.

Some HIV literature [Barlow: 1992; Morrison: 1992; Melvin: 1996; Bennett, Casey and Austin: 1996] has reported the importance to HIV-positive women of caring for their children, without analysing such findings in terms of identity, or their effect on service use. In formulating my initial topic guide, I was careful not to ask many direct questions relating to the respondents' children. I wished to avoid equating the women's interests with those of their children, a flaw of much of the early literature and policies on women and HIV infection [Henderson: 1992; Scharf: 1992], particularly in the United States [Centers for Disease Control: 1985; Francis and Chin: 1987; Bayer: 1990; Selwyn et al.: 1990b]. I wanted to emphasise to the respondents that I was interested in them as individuals, as well as as mothers. The emphasis placed by the respondents on their identity as mothers was, therefore, all the more striking. It was apparent that motherhood was a central influence on their post-diagnosis reconstruction of identity. I then used the second interviews to explore further several of the recurrent first interview themes relating to motherhood.

The significance of being a mother is, perhaps curiously, not a major focus of the literature on living with a chronic illness, examined in the previous chapter. I therefore turned to sociological studies of the experience of motherhood [Oakley: 1979; Boulton: 1983], literature on the historically variable social constructions and content of normal or good motherhood [Rich: 1977; Smart: 1996; Silva: 1996;

Woodward: 1997; Duncan and Edwards: 1999; Silva and Smart: 1999], as well as cultural commentators [Greer: 2000], in interpreting the data and analysing the predominant ways in which the respondents constructed their identities as mothers. Recurrent themes included the respondents' emphasis on prioritising their children's needs, for example, at the expense of their own interest in developing intimate relationships. In this way, motherhood as a source of identity was prioritised over partnership. Other themes included the respondents' explanation of their own continued existence, in terms of the need to guide their youngest child to adulthood. In the meantime, the respondents emphasised that their duty was to try to ensure a normal childhood for their children in potentially abnormal circumstances.

These findings highlight the central role played by motherhood in the respondents' construction of a moral post-diagnosis identity, and the consequent importance to them of establishing and protecting identities as normal, and therefore good, mothers. Once again, therefore, normality seemed to offer protection. The respondents were also acutely aware of potential threats to this identity. For example, as single mothers, on state benefits, their claims to be good mothers were likely to be contested. This project of identity was further threatened, not only by their diagnoses, but also by the general stigma attached to HIV-positive people having children, and, most acutely, to mothers who have experienced drug use problems and the scrutiny of social workers. It was difficult, even years later, for some respondents openly to discuss past events, which they saw as threatening their identity as good mothers, except to emphasise the differences in their current lifestyles. Even more difficult to acknowledge were current concerns, such as the role reversal involved in their children acting as carers during periods of illness.

In this chapter, therefore, the importance of motherhood to the respondents, and the painstaking and precarious process by which the respondents managed the risks to their identities as good mothers, will be traced. These findings will be related to the respondents' service use in the following chapter.

Motherhood As a Potential Source of Identity

The literature suggests that motherhood might be a potentially significant source of identity. Culturally, motherhood has been considered a crucial element of a woman's identity, a prism through which subsequent events, such as diagnosis with a life-threatening medical condition, will be refracted. As Kitzinger puts it:

Becoming a mother is a biological process: but it is also a social transformation, and one of the most dramatic and far-reaching that a woman may ever experience in her life [1992, 1].

The potential of motherhood in the construction of a moral narrative of identity relates to the cultural resonance of the Western institution or myth of motherhood. A central element of the Western perception of mothers has been that conventional, normal, motherhood is:

natural: the expression of a maternal instinct to want and care for children, which all 'normal' women are deemed to possess [Richardson: 1993, ix].

In the light of the respondents' post-diagnosis narrative of continuing as 'normal', the value of this association of motherhood with normality may be appreciated. As Woodward comments:

[e]ssentialist claims can be seen as empowering and as giving weight to assertions of identity, especially by those who have been marginalized and excluded or whose identities have not been acknowledged [1997, 242].

An important element in the construction of the Western myth of motherhood is the figure of the Madonna [Rich: 1977; Warner: 1985, 336 in Woodward: 1997, 250]. This idealised, sentimentalised representation of motherhood has strongly influenced expectations of mothers:

[I]nstitutionalised motherhood demands of women: maternal 'instinct' rather than intelligence, selflessness rather than self-realization, relation to others rather than creation of self [Rich: 1977, 42].

An important element of this role, at least until quite recently, has been to stay at home to look after young children [Richardson: 1993, 45; Rich: 1979, 23]. The idea that mothers should not work has also been reinforced by the popularisation of psychological theories of child development, such as those of Winnicott and Bowlby [Boulton: 1983, 4-7, 9-14]. Bowlby's ideas of 'attachment', and the importance of the intense bond between mother and child, have been particularly influential [1983, 9-14].

Until more recently, there was little academic focus on women's own experience of motherhood. My library search using the term 'mother' produced far more references to the Madonna, 'Mother Earth' and even 'mother tongue' than to work on women's experiences of motherhood. As Rich memorably put it:

we know more about the air we breathe, than about the nature and meaning of motherhood [Rich, 1986 foreword to 1979, 11].

Subsequent London-based empirical studies of white women revealed a certain ambivalence with respect to motherhood. On the one hand, motherhood did provide many respondents with a readily understood sense of meaning or purpose:

[m]otherhood is like a new job [...]. Taking on this occupational identity does have parallels with other jobs [...]. But it is crucially different in one way, for mothers are what women are supposed to be [Oakley: 1979, 249]

a comment which reinforces the strength to be drawn from the 'normalness' of motherhood. Boulton emphasises that:

a woman's sense of meaning and purpose was not an automatic response but required both a positive commitment to her children as a purpose in life and a reflection on her life in terms of that purpose' [1983, 58].

However, most of the respondents in her study had constructed an identity founded on motherhood, often drawing on conventional expectations of mothers [1983, 103].

These writers also presented however, the comments of respondents who had also experienced, temporarily at least, losses of identity and self-image as a result of

motherhood: women who felt they no longer had any sense of identity either in their own eyes [Oakley:1979, 157-8], or those of others [251-2]. Boulton emphasises the high rates of depression among mothers with young children [1983, 1], many of whom feel very isolated [1983, 204. Also see Dally: 1982, 277], as well as monopolised and overwhelmed by their children:

many women found that thinking of their children first meant thinking of their children only [1983, 97].

Both Oakley and Boulton also found that this sense of being overwhelmed by their children's needs was particularly difficult for middle-class respondents, who had given up work to care for their children full-time. Many of these women felt personally diminished as a result:

suddenly having no other occupation to call one's own may seriously injure a woman's self-concept, ideas she has cherished about herself as a person [Oakley: 1979, 54].

Similarly, Boulton concludes that:

in a society that values *production*, childbearing and child-rearing – that is, *reproduction* command little concern or respect [...] motherhood may be necessary for women to establish their femininity, their respectability, and their maturity, but childcare is a low status occupation and women's low self-esteem as mothers reflects this [1983, 22, emphasis in original].

This literature suggested that motherhood presented the respondents with a potentially powerful source of identity. On the other hand, empirical data also suggested that some women were ambivalent with respect to motherhood, for example where it threatened their identities as workers. The following sections will therefore highlight the respondents' perceptions of issues, including work, which might present barriers to their assertions of an identity as 'good' mothers.

Potential Threats to the Respondents' Identities As Good Mothers

Many writers emphasise that public discussion of motherhood often targets those considered, at any one time, to be 'bad mothers' [Woodward: 1997, 240]:

the 'bad' mother is partly constructed by not being the 'good mother' of self-sacrificing, self-effacing ideals [Woodward: 1997, 251].

The respondents' positive need to assert their identities as good mothers may be appreciated more clearly against the backdrop of the frequent stigmatisation of single, HIV-positive and drug-using mothers. In the light of recent policy emphasis on working mothers, however, the first section will address whether the respondents' identities as good mothers were threatened by the fact that none of them was working.

The Importance of Work

As discussed, several writers have recently suggested that the idea of the working mother has been normalised to a greater extent, contesting previous understandings of 'good' motherhood.

This perception may have been reinforced by government policy encouraging low-income parents to work [see Land: 1999; Gray: 2001; Rake: 2001]. To some extent, it may be said that non-working mothers have dropped out of the policy debate:

In the United Kingdom it is extremely hard for women to be mothers and workers, yet it is increasingly the case that the only route to full citizenship is through paid and active involvement in the public sphere [Smart: 1999, 113].

In Greer's opinion, this emphasis on work has undermined the cultural value of motherhood itself [2000, 248, 259]. Like Smart [1996, 33], she is concerned by greater emphasis on the gender-neutral content of parenting:

at the end of the millennium the very word 'mother' is disappearing into the de-sexed word 'parent' [2000, 272].

These modifications to the cultural significance and content of motherhood might have been expected to have dimmed its lustre, in the respondents' eyes, as a post-diagnosis source of moral identity. In particular, the greater emphasis on working mothers might have been perceived by the respondents, none of whom were working, to exclude them.

In contrast, Boulton observed that for white working-class women, motherhood may confer greater status than full-time work [1983, 100. Also see Pateman: 1992, 238]. More recent empirical research among white working-class women in London and Brighton supports this finding [Duncan and Edwards: 1999, 96, 88, 102]. For many of their respondents, unlike their white middle-class, 'alternative', or African-Caribbean counterparts [also see Reynolds: 2001], working was seen as incompatible with good motherhood [1999, 112, 116]. In Duncan and Edwards' view, the rational economic incentives on which recent government policy is based have less relevance to these women than 'gendered moral rationalities', according to which earning money is less valuable than full-time caring for young children [Duncan and Edwards: 1999].

Analysis of the transcripts revealed that several of the white, working-class respondents in this study discussed issues relating to work, even in the absence of direct questioning. This suggested that work was a culturally important issue, against which they felt a need to position themselves. On the other hand, they did not relate work to the content of 'good' motherhood in any direct or consistent way.

Some respondents (R3, R7, R11) explained that as young, in some cases, single mothers, Income Support, or its predecessors, had appeared their only option. For two of these women and other respondents, however, the issue of work appeared less important to their self-construction as good mothers than the fact they no longer had problems with drugs. In fact, R7 indicated that, for her, working was associated with drug use:

because I could never steal, I never had that in me and I didn't want to be a prostitute.

For R2, R3, R8 and R12, however, drugs had excluded them from the 'normal' world, including work, for long periods. R12 bitterly regretted giving up a job for drugs, describing her subsequent life in the following terms:

I was too busy getting money ...I used to do credit cards and that, so I was out all day using [them] [...] I'd been in that routine for 15 years nearly. Of getting up, taking drugs, [...], moving from house to house, staying with people, staying with strangers, [...] all that kind of thing, so it was a hard routine to break.

Partly because of her involvement in this lifestyle, work had never been an issue for R2. She saw her achievement as getting back to normality after drugs:

in the last seven years, it's been a big change from like drug years to straight living, even paying the TV licence [...] back to normality again [...] I feel like I can open the door and I've not got to fear anymore, living a life of crime to pay a habit.

These women therefore emphasised transformations in their lifestyle as a means of asserting an identity as a good mother. Work itself was perceived as relatively less important.

For some respondents, however, work had been important. R8 had not worked more recently because of long periods of illness. This, and the unpredictability of their condition, was cited by several women, who had previously worked full-time, for their decision to stop working:

that's me been seven years now on the sickness benefit [...] I worked for [over 20] years full-time, and it was really only because of my health [...] that I took the redundancy, and for the first four years I was really unwell (R4).

I haven't worked for several years. It's pretty bizarre actually as I've worked all my life since I was 15 actually [...] I ended up getting [ill in my thirties] and [...] that kind of screwed up my job, and since then I've been wary of starting work because I can't tell from one week to the next whether I'll be OK (R1).

Both of these women, as well as R10, R5, R6 and R9, strongly associated working with 'normality'. Most of them had worked while their children were young. By

implication, therefore, they associated working with being a normal mother, and for all of these women, not working was, or had been, a matter of regret. For R10, who mentioned this issue in both interviews, work had been a very important means of maintaining a sense of normality post-diagnosis:

I think just having my job and having friends at work, I think that's what kept me going for the first two or three years [...] definitely [...] I suppose anyone looking in would see I was just doing a normal job and going home to my family, whatever.

That these women saw it as normal for mothers to work is reflected in their often detailed explanations of why they were no longer working. R10 pointed to the effect on her husband's benefits of her continuing to work, his deteriorating health, and her son's young age. Although, stopping work had not been as difficult as she had expected, she commented that she still missed the camaraderie and sense of 'normality' associated with working.

For R1, too, this was still an issue. Although, like other respondents, she classified her involvement with committees as 'work', illness had robbed her of this aspect of being 'normal':

It would be nice to have a job and be normal, but my health just doesn't permit it [...] A normal 40 year old would have a pretty regular job, car, mortgage, insurance, and I can't have any of those things.

Similarly, R4 emphasised that work was no longer an option:

stopping working [was] really hard [...] but as the years have went on and different spells I've not been well, ...there's nothing I can do about it [...] so I have to content myself somedays. I can't go back to [factory work] as my eyes are no good enough and my hands are shakey.

Like R10, she related her reasons for giving up work in detail, suggesting a perceived need to justify this decision. She emphasised that her CD4 count had decreased to under 200, which at the time fitted the criteria for an AIDS diagnosis. She thought she had little time to live, had started on medication and felt ill.

These respondents' accounts suggest the extent to which their identity had previously been associated with working, and the continued influence of the idea of working on their sense of self. With the exception of R6, who remained asymptomatic, continued to work intermittently on the side, and had started work by the time I contacted her about a second interview, most had given up on the idea of future work. None of them betrayed any sense that working had affected their children negatively, suggesting that none of them accepted the idea that a good mother should stay at home to look after the children. On the contrary, working was seen as normal. Equally, however, unlike Reynolds' African-Caribbean respondents [2001], none of them explicitly identified the benefits to their children of their working. At the same time, it is interesting to note that R10, to an extent, and R4, in particular, both emphasised the benefits to their children of having stopped work. R4's comments were reminiscent of more traditional arguments in favour of stay at home mothers:

the look on [her] face when I was waving to her going to school in the morning and being there for her coming in at night was great.

In conclusion, therefore, for some respondents work was a less important issue than their success in coming off drugs. Several respondents seemed ambivalent about the fact that they were no longer working, however. It seemed that work was a significant cultural norm against which these respondents wished to define themselves. Those respondents who had worked for long periods were eager to point out that they had been 'productive' members of society. At the same time, the idea of 'working mothers' did not seem to have been normalised to the extent that not working threatened their identities as good mothers.

In the next section, another potential threat to the respondents' construction of their identity as good mothers will be discussed.

The Stigmatisation of Single Mothers

By the time of the second interviews, all of the respondents were single mothers. R7's relationship with the father of her children broke down between her two

interviews. R9 was still involved with the father of her child, but he was ill and did not live with them.

Since the 1980s lone mothers, particularly young, never married mothers, as was the case for several respondents, have been subjected to intense media and political scrutiny [Smart: 1996, 54, Silva and Smart: 1999, 3]. Their capacity to provide adequate parenting has been questioned. They have also been associated with the emergence of a 'criminal underclass', with the disintegration of the family, even with national degeneration [Richardson: 1993, 77; Campion: 1995, 131-2, Roseneil and Mann: 1996, 192; Duncan and Edwards: 1999, 23]. In short, single mothers have been portrayed as:

the epitome of the failure of the family: irresponsible mothers whose motives and capacity for motherhood are questionable and who choose a life of dependency [Millar: 1996, 98].

At least one of the respondents had been rejected by her family prior to diagnosis, because she was pregnant, experiencing the stigma attached to lone parents at first hand. However, none of the respondents expressed any current feelings of stigmatisation on this basis. For these working-class women, therefore, the prevailing national and policy discourse on single mothers was not a decisive influence on their sense of identity. In the same way as for many of the mothers interviewed by Duncan and Edwards, their self-image was also influenced:

by the material and social context of the neighbourhoods in which they are located [1999, 48].

Further, in many working-class areas, lone motherhood was seen as prevalent and normal [1999, 46].

The respondents' identities as good mothers did not seem to be affected by their status as single mothers. None perceived any need to comment on or justify this status. It was clear, however, that a greater challenge to their identities as good mothers was provided by HIV infection, and, where relevant, their history of drug use and involvement with social workers.

The Stigmatisation of HIV-Positive Parents

The Association of HIV Infection With Sexual Activity

The respondents' stigmatised diagnosis did present a threat to their identities as good mothers. In part, this stigma relates to sexual transmission of the HIV virus:

[t]he perfect mother [the madonna] is [...]a virgin and is idealised as asexual [Woodward:1997, 250].

The association of HIV infection with sexual activity may provide some explanation for the prejudice experienced by several respondents with respect to their having children. Several respondents were diagnosed while pregnant, and the potentially crushing effect of the incidents recounted below on their self-image as mothers is easily appreciated.

Three respondents had been advised to have abortions, even relatively late in their pregnancy. R8 and R12 refused, but R9 took this advice despite her pro-life views, a decision which still caused her great distress, as related in the previous chapter. R2 was sterilised while still a teenager. Although this operation was carried out at her own request, it seems unlikely that it would have been funded by the NHS in many other circumstances. R11 was sure that the only reason she was not advised to terminate her pregnancy was that she was nearly eight months pregnant at diagnosis. However, she received no reassurance, and little compassion, from medical staff:

the only information they would give you was very gory. It was like...give you two years maximum to live, and your child's definitely gonnae be born with AIDS, and that was the be all and end all of that.

Several respondents mentioned appalling treatment by maternity hospital staff. R8 recounted that after her baby was born, she was 'treated like shit'. Her meals were left outside her room, and nurses refused to bathe her baby. R1's, R6's and R7's accounts were very similar, and also referred to stigmatising stickers being placed on the doors outside their rooms. For example:

I was 19, I was still pretty naive [...] the medical staff make it very clear that they have an opinion towards you [...] basically scum,...and handing the baby over to

me with gloves, in open ward [...] I had to give birth [...] in an auditorium, there was workmen working next door, no sign, no bell, no nothing [...] everybody's entitled to the feeling that you've had a child, and they took that away from me (R6).

Pierret [2000, 1593] and Bennett et al. [1996, 185-6] point out that many HIV-positive women feel the stigma attached to their pregnancies keenly, and for long periods thereafter. In this study, R11 reflected that at several points since her diagnosis, she had felt that her children would be better off without her. R7, R9 and R12 preferred not to mention the fact that they had had children some time after their diagnoses, suggesting a certain level of residual guilt.

The Residual Stigma of Previous Drug Use or Involvement With the Social Work Department

An even greater threat to some respondents' identities as good mothers was posed by previous drug use or involvement with the Social Work Department [SWD]. As Barlow indicates:

[d]rug injecting women have gone against society's perceived role of women as nurturers [1992, 26].

Although not all of the respondents had used drugs, all of them felt they had been 'tarred' by this brush. Some respondents indicated that, although they had never used drugs themselves, others, including service providers, assumed that they had. Similarly, several respondents felt that they had been pushed into attending the City Hospital, instead of the GUM Clinic, for HIV services. Since the City Hospital was associated by all of the respondents with drug use, this 'ghettoisation' was perceived to be the result of stigmatisation. To some extent, therefore, the prejudices affecting drug users affected all the respondents, irrespective of actual drug use.

For those respondents who had used hard drugs during and after pregnancy (R2, R3, R4, R7, R8 and R12), or had had substantial involvement with social workers (R7, R11, R12), these issues were particularly sensitive. Although I did not probe these matters, the respondents kept returning to them. Further, the omissions and contradictions present in their accounts, for example as to whether or not they had

given up street drugs before or after becoming pregnant, suggested that these issues were associated with actual or potential 'transgressions' of good motherhood.

One respondent, for example, initially stated that, barring one relapse, she had been on methadone, and off street drugs, since her pregnancy:

[w]hen I was pregnant I got put on methadone and I've been on methadone since 1988. But I had one time when I went on the street but it only lasted a week, and then I thought to myself this is stupid, you know I'm gonnae have to start stealing, and it took me a long time to get the respect from my family back and everybody, and to be able to walk past these drug dealers and everything [...] But I had to do it for my daughter.

She wished to emphasise that pregnancy had changed her life immediately, and that her child had never been affected by her drug use. However, she later recounted:

I hid [child] because she was a baby, [...] and I was on drugs and I went to the house to get [...] my weekly money and the social worker says to me, you can either walk out of here and never see your baby again, [...] or you can come in here be a mother, look after your child and get on a methadone programme. So I walked out of the house but I got to the car and my partner says 'no come on we'll just go on the methadone together' and that was it.

A similar discrepancy was apparent in the interview of another woman, who, in her second interview, recounted that she had been 'on the temgesics' only up until she had had her first child. In her first interview, however, she had spoken of taking drugs several years after having had both children:

I didnae take drugs through pregnancies ehm they would put me [...] on like methadone through my pregnancy or reduced me before the bairn was born, so my bairn wouldn't be born with a habit, but as soon as I had the bairn it was just like I went back to where I'd left off [...] it's just too easy for me to take the drug and just forget about things.

Other women skirted around aspects of their past they preferred not to highlight. One respondent, who had spent part of her teenage in an approved school, indicated in her first interview that she had had no other previous contact with the SWD.

Further, she stated that her *first* child lived mostly with her parents because she had been diagnosed during her pregnancy and was not expected to survive. In her second interview, however, she said that she was diagnosed when pregnant with her *second* child, and that the SWD had removed this child for some time because of problems with a violent partner. This ‘admission’ therefore suggested that her first child had been brought up by her parents, not because she was expected to die, but for other reasons, perhaps relating to her parenting skills at that time.

These examples might be taken as illustrative only of the omissions and inaccuracies which normally occur in conversation, for example out of a need to use shorthand. The use of such shorthand seems particularly likely in an interview in which such sensitive issues are scrutinised by a stranger. Further, the second quotation from the first respondent in this section may reflect a desire to be loyal to her late partner, rather than any ‘truth’ of what happened. However, some of these discrepancies could not be explained in this way as they were answers given to direct questioning. This suggests that these respondents felt considerable guilt about past events, which they saw as ‘transgressions’ of their role as mothers, and as threats to their current reconstruction of identity as good mothers.

It was particularly difficult for respondents to acknowledge that their drug use might have affected their children, for example in some of the ways indicated in recent studies [McKeganey, Barnard and McIntosh: 2002]. R2 and R3 were adamant that their drug use had always been under control and that their children had been provided for properly. However, one of these women had spent time in prison, separated from her children. Another respondent’s child had been severely injured as a result of inadequate supervision. R2 did say that her child had seen things she should not have seen, but the context of her remark is revealing:

She’s seen stuff in her early years. In the last seven years it’s been a big change from like the drugs years to straight living, even paying the TV licence, ken [...] back to normality again and I like it that way.

She used this ‘admission’ therefore as an example to measure the distance she had moved away from her previous drug-using life to become a good, normal mother,

and to emphasise that having a child had been a strong, if not immediate, catalyst for change.

The Respondents' Difficulties Discussing Current Problems With Childcare

The respondents were therefore acutely aware of these potential threats to asserting identities as good, or even adequate, mothers. In the light of their desire to consign such concerns to the past, and to establish and protect their identities as good mothers, the difficulty for the respondents of discussing current childcare problems may be appreciated. Key problems, such as illness, were often omitted from their accounts: an eloquent testimony to their potential to undermine narratives of good motherhood. Moreover, issues such as children acting as carers tended to be discussed defensively.

As Melvin explains, for a mother, illness can mean:

having to think not only about [...]her own mortality but also about losing or sharing the parenting role [1996, 226].

Life-threatening illness, particularly, threatens to undermine a mother's role. As Champion points out, mothers with such illnesses would not be considered as candidates for adoption [1995, 45].

Another difficult issue, connected to that of illness, was that of role reversal where the respondents' children, often inevitably, became carers. Such situations may threaten an individual's identity as a good parent since it is generally assumed that:

[p]arents can only be normal if they prove themselves to be totally self-reliant at all time [Champion: 1995, 145].

Further, caring is perceived by social work professionals as potentially damaging to children:

where the parent as carer and child-as-dependent roles are reversed, the young person could face complex psychological problems, with their education and friendships damaged by the stress of caring [Community Care 22.2.90, in Champion: 1995, 142].

Many of the problems of child carers were highlighted by Aldridge and Becker's ground-breaking study. They found that child carers were:

consistently neglected by both family and friends, as well as formal professionals who are paid to care [Aldridge and Becker: 1994, vi].

Campion questions this assumption, pointing out that child carers often have very close relationships with their parents [1995, 144-5]. This may be the view of R12 with respect to her nine year old daughter:

She always reminds me 'take your pills, Mum, take your pills'. I'm on 34 pills a day so like it takes a lot out of me and she always makes sure that I take them on time. She's a wee grown up for her age. I think it's because she hasn't got any brothers or sisters and she's with me all the time. But she's great.

It was clear that several respondents did see this issue as a problem, however, although one they found difficult to discuss. R11 was ambivalent about her children caring for her when she was ill. She did not like the fact that her children had helped her. At the same time she was touched by their actions, and felt they had wanted to do it:

they're too grown up. It's wrong for kids to be carers [...] They like to help me.. 'have you taken your pills today?' When I was very ill, I didn't like it that the kids were helping me but.... they were there for me.. taking me to the loo and when I needed a drink at three in the morning.

R2 also recognised that her teenage daughter took a lot of responsibility on to herself. Her comment that:

I'm not trying to put all the responsibility onto her – my brother is my carer.

suggested a level of defensiveness around this issue.

Similarly, R4 voiced her concern that her daughter should go out and live her life. Other comments indicated why it might be difficult for her now adult daughter to do so, however. This respondent, who had received virtually no support over the years from family or services, had installed her daughter as her main carer, a position now

very important to her. In fact, she was careful to reassure her daughter that this position had not been usurped by her new counsellor:

[my daughter] says to me, you will talk to me. I says I talk to you first and foremost and then I would discuss it with the counsellor. I would never discuss anything with anybody without discussing it with [daughter] because she is my main carer.

This issue was particularly difficult for R1, who was ill at the time of her interview and socially isolated. Her praise for a respite agency which allowed her pre-teenage son to:

be a child as opposed to a child carer

indicated her awareness of this issue. Her interview revealed, however, that her son often made his evening meal, and that she relied on him for company. In response to a question asking her about times she felt were difficult, she indicated she had such moments about once a month when:

Just something might trigger me off being miserable or having an argument with [son] and he stomps off to play with his pals and I'm left nobody to say anything to.

In general she spoke of him in markedly adult terms. She was, however, very resistant to suggestions by social workers that her son's behavioural problems might be linked to her condition, or to the above responsibilities. Similarly, she preferred to attribute another child breaking links with her, to that child's partner, rather than to the high level of responsibility this child had taken on while still at home.

In conclusion, the issue of children caring was a particularly difficult one for the respondents. Like Aldridge and Becker's parent respondents, it seemed that they often preferred to keep caring as a private, family matter [1994, 9]. They may also have been worried about divulging the role played by their children for fear of SWD intervention [1994, 31]. Further:

it may also be the case that parents do not really want to acknowledge their own pain or guilt over having to receive informal care from their children [1994, 9].

Themes Discussed By Respondents to Establish Their Identities As Good Mothers

It was very difficult, therefore, for many respondents to discuss issues that might undermine their identities as good mothers, even with a researcher with no influence over their lives. In contrast, most respondents emphasised the positive choices they had made with respect to looking after their children, reinforcing their identities as good mothers. Once again, it should be noted that most of these issues were not raised in response to direct questioning relating to motherhood or children, thus underscoring the importance of these issues to the respondents' post-identity construction of identity.

The Importance of Putting Children's Needs First

Establishing oneself as a good mother requires an appreciation of what a good mother does. One central element of conventional good mothering is putting the child's needs first:

In the Judaeo-Christian conception, the woman alone devotedly, unselfishly and wisely gives herself to the task of reproducing new generations. Regardless of her own needs, socio-economic conditions or husband-partner, the mother must always subject herself to the ideal [Silva: 1996, 10. Also see Oakley: 1979, 4, 206; Pugh et al.: 1994, 44; Campion: 1995, 61-2]

Many of the mothers' comments, reported by Boulton [1983], Oakley [1979] and Devlin [1995], provide confirmation of this expectation, in their recurrent presentation of their own desires with respect to childbirth and motherhood as 'selfish'.

The importance of putting their children's needs first was often raised by these respondents while discussing their attitudes to initiating and continuing intimate relationships. Partnership might have provided the respondents with another important source of identity. However, most respondents considered it difficult to

reconcile partnership with their dominant post-diagnosis source of identity: motherhood. As such, their comments contrast strongly with the views of male members of a self-help group interviewed by Crossley [1998], who rejected any notion of duties in relation to their sexuality or having children. Several employed the discourse of rights, advocating the need to 'take back [their] sexuality' post-diagnosis. Only a female member of this group referred to ideas of obligation or duty with respect to their sexuality or having children [1998, 521-3; also see Rhodes and Cusick: 2000].

One respondent, partly perhaps because her children were older, did not discuss her intimate relationships in the context of her children. Even so, her use of pronouns (emphasised below) indicated tensions, between her attitude of defiance, her experience of the effects of her diagnosis on her sex life, and her tendency to talk in terms of HIV-positive women in general:

He's been *my* lover for x years [...] [x] years without contraception [...] and he's OK like ... so this idea that you catch it from women..it's ruined *our* sex lives you know, because men'll no come near HIV women because they can become infected.. but he's proof that you dinnae you know, it doesnae matter what you do.

However, later in the same interview her remarks hinted at the difficulty even this woman might feel at talking in a non-conventional way about sex and relationships:

HIV does take that away from you .. your confidence, self-esteem, feeling like a woman [...] *you* think you're nothing, you're no worth anything, you cannae go out the dancing and pick up a guy and take him home and have a quick bonk [...] *I've* never allowed it to affect my sex life [...] even though I'm positive you know I'm still a person and it doesn't change me [...] this is my third guy since I've been positive ... that's terrible.

Most respondents consistently identified a conflict between their children's interests and their own with respect to this issue, whether they were involved in long-term relationships (as were R2, R7 and R9) or considering initiating new ones.

R7 emphasised the effects of this perceived conflict of interests on her long-term relationship with the father of her children:

I mean I've really [had] nae sex life at all [...] for the last two years.. [...] because [...] well my partner's no positive and he really has to be there for the bairns at the end of the day. And I'm that paranoid [...] I'm thinking I'll gie it to him, which is stupid because we've had unprotected sex for all these years. I didn't even know I had the virus and nothing [happened]. [...] So I mean it's like finished my sex life.

Her overwhelming desire to protect her children's interests had therefore damaged her relationship with her partner, which broke down between her two interviews.

Most of the concerns expressed in relation to this perceived conflict of interests were raised with respect to initiating new relationships. Several respondents, who were not in relationships at the time of their first interviews, expressed difficulties with this idea, while indicating, somewhat sheepishly, that they would like to have someone.

R4 emphasised that her primary concern on diagnosis was to 'keep [her] energy and strength for bringing up her daughter' rather than getting involved in a relationship. Her account suggested a perceived duty of self-sacrifice:

I always think it's hard to bring new people into my life because then they're just gonnae get hurt [...] I knew a lad years ago [...] and he wanted to start a relationship but he had two small boys. And I says no [...] the thought of having to tell they two kids, or for [them] to get attached to me.

In some cases, the respondents' concern that relationships were incompatible with their children's interests related to their experience of previous violent relationships. R2, R3, R4 and R11 all mentioned having been beaten by previous partners, while R6 hinted that this might have been the case. R4 explained that a relationship had turned violent after her first, estranged, husband had died of an AIDS-related condition, and her then partner had belatedly acknowledged the gravity of her condition. As a result, she had been forced to sell her home. Other respondents mentioned longer periods of sustained violence.

Several respondents also emphasised that bringing a man into their life might affect their own and, particularly, their children's, confidentiality [see Melvin: 1996, 227]. Although several respondents had adopted policies of openness with respect to their

diagnoses, most did not want their children to be affected by this disclosure. As R11 put it, the relationship might be over quickly, and the man might then ‘blab’, or, as she had experienced, spray her door with the words ‘AIDS-riddled scum’. Similarly, R12 explained:

If I was to have a relationship with anybody, I’d have to explain to them that I was HIV. And if it was to be a short relationship then they would tell someone else [...]. I need to protect it for my daughter because people are gonnae say your Mum’s got AIDS, your Mum’s this, so that’s the reason I keep it quiet.

R4 and R2 referred to the same concern, as did R5:

I mean it doesnae bother me but I dinnae want her being taunted at school.

At the time of their interviews, these issues were put into sharp focus for two respondents by the possibility of new relationships. R12 confided that she had been asked out for the first time in the five years since her partner’s death. The prospect of tenderness was hugely tempting for her, but she was concerned about the potential effects on her daughter:

I feel lonely, I feel alone but I wouldn’t bring another man into [daughter]’s life.
[...] It’s hard.

By her second interview, R4 was feeling her way around the effect of a new relationship on her adult daughter. She was enjoying the new horizons the relationship brought her, but feeling that her daughter did not approve, she had panicked:

I mean it’s hard enough for [daughter] now without bringing someone else into the circle.

To resolve her unease, she had turned to her counsellor, who had ‘legitimated’ the relationship in her eyes by reassuring her.

Several respondents indicated, therefore, that they found their desire for a relationship difficult to reconcile with their identities as good mothers, and the consequent duty to prioritise the needs of their children. The transcripts of R6, R8,

R10 and R11 suggested a potential compromise with respect to this issue: non-cohabitation.

R11 joked that the perfect partner would be an offshore worker, putting the case in the following terms:

I'm no wanting somebody with me 24 hours no. I mean it's the kids and that as well, they've been let down too many times, by failed relationships of mine that I just think, no, not until they're a good bit older and out of my hair would I want that sort of commitment.

R8 who had started perhaps the most solid new relationship of these women, between her interviews, was also adamant that she would never live with her new partner, as she did not want to 'look after' him as well as a young child.

On reflection I realised that similar arrangements had been maintained by two women in long-term relationships (R9, R2) and was being adopted by R4 in her new relationship. The reduction in means-tested benefits consequent on cohabitation might be one reason for this. More important however, seemed to be the respondents' concern to reconcile their desire for a relationship with their concern for the potential effects of such a relationship on their children.

The respondents' concerns about the potential effects of new relationships on their children may be shared by many separated or bereaved parents. The fact that they placed such emphasis on this issue, in the absence of direct questioning, reflected their desire to highlight their determination to be good parents, and, underlying this, their concern that their claim to this status might be contested.

In the following sections, the respondents' concerns relating to the effect of their HIV infection on their capacity to be good mothers will be discussed.

Being a Good Mother in Abnormal Circumstances

As mentioned, the decision to cohabit with a new partner is a potential concern for all separated mothers. The next few sections will, however, focus on the respondents' discussions of concerns not typically shared with most other women,

notably their own potential disability and death, and the practical and emotional effects of these issues on their children. These concerns were of paramount importance to the respondents, many of whom had initially been told they would die within a few years of their diagnosis. The respondents' response to these issues formed a crucial element of their establishment of identities as good mothers.

Several writers have suggested that recently there has been an expansion in the content of 'good motherhood' from practical tasks to:

the immense realm of psychological care and nurture of the child [Smart: 1996, 46; see also Silva: 1996, 30; Pugh et al.: 1994, 42].

In this study, the psychological and emotional issues raised by diagnosis were particularly complex. Many respondents highlighted their difficulties disclosing their diagnoses to their children, and preparing their children for a future without them. Similarly, most respondents worried that their chronic fatigue prevented them from keeping up with their children's normal activities. Their concerns reflected a conflict between their acute awareness of the potential abnormalities of their situation, and their desire to ensure a normal childhood for their children. In the first section, the respondents' primary concern, that they should not die until their youngest child reached adulthood, is discussed.

A Mother's Fundamental Duty to Survive

'You almost died', a nurse told her. But that was nonsense. Of course she wouldn't have died; she had children. When you have children, you're obliged to live [Tyler: 1992 in Devlin, ed.: 1995, 166].

The most common aim expressed by the respondents, whenever diagnosed, and however old their children, was to survive to protect their children.

As discussed in the previous chapter, this concern, emphasising the importance of survival, would be categorised by Ezzy as an example of a 'linear' post-diagnosis narrative. His advocacy of a 'polyphonic' narrative, accepting of death [2000, 613-6], would likely be seen by these respondents as a betrayal of their identity as mothers, whose primary duty must be to survive for the sake of their children.

R11 described how she set herself short-term goals for survival relating to stages in her children's development, such as starting primary or secondary school. Nearly all the other respondents spoke of their goal of surviving until their youngest child's sixteenth birthday. Several respondents mentioned this aim in their first interviews. Struck by this assertion, I incorporated a question relating to this milestone into the second interview topic guide. In the event, two respondents discussed this milestone in their second interviews unprompted.

Expressions of this aim included:

I've always said that since the day I was diagnosed, that was my main concern [....] that's still my main aimto be here when he's 16 (R10).

My future has been from the day I found out, my hope has been that I make it to [daughter]'s 16. Then I've done my duty as a mother (R2).

My daughter that worries me I just think so long as I can still be here when she's 16 (R5).

I think the main thing with me was my daughter being so young.. you know, that was the worryumm and the aim was just to get her to her 16th birthday (R4).

I wondered whether this specific milestone was selected with reference to the legal significance of this age. Entitlements to Housing Benefit and Council Tax Benefit do not decrease automatically when a child reaches the age of sixteen, but the respondents may have been influenced by the assumption that their children would leave school at that age to start work. R1 also mentioned that, if she stayed alive until her son reached sixteen, he would have the right to take over her council tenancy if she died.

Most of the respondents' explanations of the significance of the age of sixteen, however, reflected a strongly-held perception that this age marks the end of childhood, and also, therefore, of the high watermark of parental responsibility:

You've got it in your head that they're yours until they're 16 I think [...]. Once they're 16, [...] it's like you've done your best [...] in the most important points of

their life [...]. I think so anyway, like you bring them up and teach them right from wrong, show them the way if you like (R10).

That was the age when they could look after themselves – when bairns become adults (R8).

When you're 16 now, you're big, you're like allowed to work, able to get a house, not allowed to go to pubs or smoke stuff right enough, but you're allowed into pubs and to have sex and I thought if I do that, in my mind I've done my duty as a Mum (R2).

The age when they're responsible for themselves [...] do everything they need for themselves. They dinnae need anyone else to be their guardian or anything [...] It's like cutting the umbilical cord (R3).

Let's get her until she's 16, an independent individual that if I died then she would be able to run a house [...] you know she could look after herself (R4).

This association between 16 and the end of an absolute parental responsibility was also a finding of recent research into teenage homelessness [Joseph Rowntree Foundation: 1997]. As in this study, far greater cultural significance was attached to the age of sixteen than is actually provided for in law, or by the benefits system.

The importance of reaching this milestone, in terms of the respondents' identities as good mothers, was also evident in many other comments. These remarks further highlighted that most of the respondents had drawn on motherhood, to a far greater extent than, for example, partnership or work, in their post-diagnosis construction of identity. For example, several respondents attributed their determination to look after themselves, their capacity to fight off illness, or their resistance of suicidal thoughts, to being mothers.

R1's remarks were made in the context of recent SWD intervention into her family:

if it keeps [my son] and myself together as a unit, then I will ask, I have to, as otherwise I'm going to end up losing my child and if I lose [him], I think I'd lose hope. Without [him] to worry and care about, I wouldn't care about me half as much [...] Without [him] I couldn't manage on my own and probably wouldn't

care. I would lose interest [...]. So I think having children in a lot of ways forces women to keep going.

In her view, men, even fathers, did not think in the same way, and therefore were more likely to die.

Other respondents focused on periods of illness. R5, for example, emphasised that her survival was partly dependent on her feelings of duty and love for her child:

if I didnae have her, that's what keeps me going. [...] Last year when I was ill [...], I would have committed suicide cos it was that bad..... I needed a blood transfusion, [...] an oxygen mask on four times a day, I had a drip on for 18 hours a day [...] it was horrible, the worst thing that I've ever been through in my whole life..and if it wasnae for my daughter I would have gave up.

For R12, survival was a current concern. She was to be discharged from hospital the day after the interview, after having been very ill with an AIDS-defining condition. The precariousness of her health was a recurrent, poignant theme of her interview:

I'm like a cat with nine lives...it's the third time I've been ill with chest problems.
I'm fully blown AIDS now. So that's it...that's me.

On several occasions however, almost within the same breath, she exhorted herself to keep going until her daughter reached 16, and mentioned plans to stop smoking as part of making sure she succeeded.

Some of these declarations might be interpreted as sentimental, throwaway remarks aimed at emphasising their affection for their children. However, in a context where mortality is a real threat, and more present in these women's lives than in the lives of other women of a similar age who are not HIV-positive, it seems that such an interpretation would be unjustifiably cynical.

The level to which motherhood, including the duty to survive, was incorporated into the respondents' identities was further underlined by fears experienced at the actual approach of their youngest child's sixteenth birthday. Even though her son was aged

under 10, and she was sure she would survive, R10 described herself as ‘paranoid’ about making it to this milestone:

I go through stages... I don’t think about it and then all of a sudden you are thinking about your own future whatever.

Similarly, R7, whose children were still quite young, preferred not to think about this milestone in her second interview, as her health had taken a turn for the worse.

R3, whose children were older, had tied her own mortality to this milestone extremely closely:

When they turned 16 I got a bit paranoid, you know cos I thought have I lived to this age for that reason, and now am I gonnae die? You know, because my quest is over, that sort of thing.

For R2 this issue was of immediate concern as her daughter turned 16 in between the first and second interviews. In the first interview, she recounted her mounting concern at reaching this milestone, and how she intended to cope with it:

[Daughter]’s 16th birthday is actually coming up on [about four months] which is worrying in a way because that’s when my hopes went to [...]. A friend from years ago [...], that was her hope as well, and when [her youngest] came 16 she just went seriously ill thinking she was gonnae die now [...]. But I’ve learnt now to make it when she gets to 16, to make it 21. And to do it that way, because that’s what’s keeping me going.

By her second interview, reaching this milestone had become a major source of anxiety:

all these years, you’ve been going to 16, the whole 16 years, well me 13 years, going 16, 16, 16 and it’s now fucking here and it’s like oh wow.. you never think for a minute that you’re still gonnae be here [...] You hope you [are] but with all the people that have died on the way you think chances are ...

It was difficult for her to disassociate reaching this milestone from other current concerns:

All of a sudden, 16, bad result, doctor negativity, DLA review, it's like boom, boom, boom, boom.

R2's initial optimism as to her ability to negotiate this milestone, and therefore the end of her most important period as a mother, had evaporated. Her deteriorating health reinforced a perception that her self-definition as, primarily, a mother, would no longer be credible; further, that her survival would no longer be necessary, as no other source of identity could provide such a compelling reason to justify her continued existence.

R4's interviews suggested that she had not re-negotiated her identity when her child reached sixteen. Now that her daughter had reached her twenties, she was having to engage in this difficult process:

I was higher than her [on her birthday] because for years I thought it was like, get her to her 16th birthday, get her to her 18th birthday [...]. And it was strange because I sortae feel like you know, I'll always be there for her but [...] now my job's done [...] now that she's made all the right decisions over the last year for herself [...] I feel now that I've got the chance of having another life for myself (R4).

Her sense of achievement was palpable. However, she emphasised the role of a counsellor in persuading her it was now acceptable to focus on herself, and her new relationship:

in the run up to her [birthday] I felt a bit like [...] what am I gonnae do with my life? [...] Seeing the counsellor as well, she's helped me realise that [...] because my health is at a good stage after all these years I should be trying to make the best of my life as I can.

R4's account suggested she was still unsure of this new, more self-focused, identity, while also drawing to a greater degree on partnership. R3 was the only respondent who, after initial difficulties, seemed to have successfully re-negotiated her identity after her son had reached 16:

When my son was 16 it was like freedom you know, and then bang my daughter has a bairn and now I'm responsible for that child [...]because she's so [...] laidback you know.

She resented taking on a further parental role in respect of her grandchild, and was not embarrassed to say so. Being a grandmother conflicted with her newly developed involvement in community groups, another potential source of identity which will be discussed later in this thesis.

Survival for their children's sakes was therefore perceived by most respondents as their first duty. The fact that concerns about their own potential mortality were primarily expressed with reference to their children illustrated the extent to which their identities were interwoven with motherhood.

Several other recurrent themes further exemplified the respondents' concern, as mothers, to negotiate and counter the abnormality of their situation, notably their potential illness and death, while trying to ensure that their children enjoyed a 'normal' childhood. These themes represented further positive choices made by the respondents to try to be good mothers to their children in spite of the huge odds they faced.

Preparing for Death and Educating Children To Be Independent

Inspired by the concerns of several service providers I interviewed, I included questions in the second interview topic guide on the respondents' legal and financial preparations for death. Some respondents' answers revealed that they also considered making wills to nominate their children's guardians as extremely important. Others, however, placed greater emphasis on less formal preparations for their children's future, such as educating them to be independent, and to avoid the mistakes they believed they had made.

R4 and R3 had made wills, but emphasised that the primary significance to them of this formal process was the intensification of their own will to survive:

I [...] looked at my sister and the way she brought up her kids and I thought, hold on a minute, my kids arenae going to you [...] I dinnae like the way your husband

talks to your children. [...] And I decided [....] I'm no gonnae go you know, I'll have to stay until they're 16 at least (R3).

Like R11, R2 was concerned about her health, and was in the process of making a will:

I want it done right because too many of my friends have died leaving them with like new partners who are maybe negative. The kids have just been kicked out the minute [...]. My friends and family have all been instructed by mouth but I know [for the law] I have to put it in writing which I am gonnae do (R2).

Several respondents on high rates of Disability Living Allowance [DLA] mentioned having set up bank accounts to provide, in the event of their death, a financial cushion for their children.

R8 had tried to make a will on several occasions, but found the process too painful. Of more significance to her than such formal preparations for death, however, were her efforts to educate her children to avoid the mistakes she had made. Several other respondents also mentioned this concern, which may partly reflect the common hope of many parents that their children should have better lives than their own [Boulton: 1983, 110]. The respondents' early experiences of injection drug use, unprotected sex and pregnancy, however, intensified this concern.

R7, for example, was very happy there was no drug-dealing in her area, commenting:

I'm really hoping that they dinnae go the same way as me [...] but they've been brought up real different [...] I was really strict with them, so [...] they do what they're told [...]. Whether it'll make any difference, I dunno.. I hope so ehm, I dinnae want them to do anything that I done.

R8 and R3 were concerned that their children should know the 'facts of life'. This was important to several respondents who had had children, and been infected with a sexually transmittable virus, as teenagers. When asked what had changed for her since diagnosis, R8 said:

Life's been more important to me since then ehm..just wanting my kids to know all the facts of life and things like that.

This response to a very general question illustrated the importance of this aim to her concept of a good mother.

At the time of her interviews, R3 was very upset by her daughter's teenage pregnancy, which made her feel that her educative efforts had failed. Again, in response to a general question, as to what she had felt difficult to cope with since her diagnosis, she said:

my daughter falling pregnant, [...] would have been normal if I wasnae positive.. but that was the last thing in the world that I expected to happen. I'd taught my daughter everything about safe sex, and then she was pregnant. [...]. That gave me full-blown AIDS [...] it really knocked me for six [...] I was just devastated for my daughter because I'd no been able to help her, her being so young.

Another important concern was raised by some respondents, who had been diagnosed in the mid-1980s, and told they were likely to die within a short period. R4 and R3, for example, both recounted that they had insisted their children become independent from an early age. R4's daughter had had the use of her cash card at the age of 14, and had been asked to make her own decisions from an early age. R3 made an explicit connection between developing her children's independence and her own potential death:

Teaching them and making them independent- that was the hardest thing [...] for me as a mother. Knowing that I had something and I felt so guilty because ...my kids were gonnae be without two parents because of my stupidity as a teenager, [...] taking drugs.

Both of these respondents' children were now adults. In her second interview, with her son in the room, R3 criticised this policy:

You'd be able to do that if I wasnae here, you wouldn't have to depend on anyone, you know be independent and sticking that into their heads. But I think in doing that I put 10 years onto their lives. They missed a fair bit of their young lives you know because I forced things on them about sexual issues.

With hindsight, and perhaps because of her continued survival, R3 was concerned she might have over-emphasised this aim, depriving her children of important aspects of their childhood. Her comments illustrate the difficulty, shared by many respondents, of negotiating the implications of her diagnosis for her children, while trying to ensure that her children enjoyed a normal childhood. Another difficult issue, raising a similar dilemma, is discussed in the following section.

Telling Your Children You Might Die

Several respondents emphasised the difficulty of telling their children about their diagnosis and its potential implications. Several of the service providers I interviewed regarded such discussion as necessary for children's welfare, whatever the physical condition of the parent. This is also reinforced in the literature [Melvin: 1996].

Disclosure, however, requires the respondents to raise the major potential abnormality of their situation as mothers directly with their children, to some extent shattering their impression of a 'normal' childhood. Several respondents, whether they had decided on disclosure or not, expressed concern about this approach, particularly where the child's father had already died from an AIDS-related condition.

Some respondents had resisted telling their children, as they could not accept that receiving this information could be compatible with a 'normal' childhood. For R3, in particular, disclosure conflicted with her aim of being a good mother. As discussed earlier, several respondents were also worried that disclosure might expose their children to being seen as different, and to potential victimisation by classmates, should the information become known at school [R4, R10].

Other respondents had disclosed their diagnosis only after their children had voiced their own suspicions. Their experience suggests that, as research has shown with respect to adoption, children may pick up on the 'undercurrents' of family secrets, and worry about them [Melvin: 1996, 227]. Pincus and Dare liken an undisclosed adoption to:

an elephant in the corner of the sitting room which everyone affects not to notice [1978, 166].

Some further respondents had decided to disclose this information, and acknowledged that their children had guessed more than they had realised:

She's so intelligent [...] doesn't miss anything [...] I didnae realise how much she knew... about the virus and that, and when she was telt, I was really surprised, because she was in a right state, but obviously we got her into play-schemes and that here (R7).

R7 remained very concerned about the effects of disclosure on her elder child, and on her relationship with this child, however. Although not overtly questioning the wisdom of telling a younger child, she was adamant he was not yet ready for this information:

we're kind of working around to see when's the time to tell J [...] L's really mature like 10 going on 20 and has known for a year now. Whereas, J I feel that's my bairn and [...] I cannae do this to him ...cos I know how it's affected L.

R8 also had several children and her comments illustrated the potential difficulties of disclosure where there are children of different ages and levels of maturity in the family:

[the] process of [...] telling each one of them at different times is quite [hard] ..and then after telling them, questions that were coming up. Then trying to hide them.. like I can remember my youngest child before she knew, she was like [...] Mum I know you've told [the others] something and you've no told me. And that was [...] quite hard.

R6 had started to talk to her daughter about her condition at a very young age. She raised another potential problem relating to disclosure, however, namely, the difficulty of managing the long-term emotional impact of this information:

She knows I've got bad bugs in my blood [...] she knows her dad's dying [...] I'm trying to make it affect her as little as possible [...] but [...] it'll come as a big shock one day and go woof! after a gradual build-up.

At the time of her first interview, R8 was encountering this type of delayed emotional reaction from her adult son, who had known of her diagnosis for several years. Her concern was evident in that she raised the issue in response to a very general question, describing how he would ‘clam up’ when she tried to talk to him about HIV infection:

talking to my children is quite hard you know [...] if you die..It’s not a subject that really gets brought up you know [...] like my son [...] he just doesnae like talking about it at all ... he just cuts off all the time when you try.

By the time of her second interview, however, this situation had improved after a long talk. She was hoping this breakthrough in communication would continue:

I had a really good talk with my son about HIV [...] a couple of months ago which went really well [...] but it only happened the once...but [...] since that night it’s been more open, cos we sat up for hours talking, so I don’t know if it made a difference.

Several respondents therefore spoke of their anxieties about the long-term effects on their children of disclosure, in terms which emphasised the difficulty of ‘normalising’ this information. The respondents’ concerns relating to another threat to their ability to provide a normal childhood for their children are discussed in the following section.

Finding the Energy to Be a Good Mother

Several respondents worried about finding enough energy to ensure that their children participated in ‘normal’ childhood activities. Such concerns might be held by any exhausted parent. For these respondents, however, this concern was intensified by the chronic fatigue associated with their diagnosis, and the need to preserve their own health. Ensuring their children received sufficient attention potentially conflicted with their duty to survive. At the same time, not being able to find enough energy for their children could lead to a loss of identity as a mother. This problem was described by a service provider for an agency helping families affected by HIV whom I interviewed:

People get so debilitated because they have HIV, they feel bad because they can't do more with their children. Terminal illness brings its own issues. People have negative reactions to themselves as mothers.

The threat that this issue posed to some respondents' identities as good mothers was suggested by the emphasis they placed on assuring me that their children did not miss out. R2, for example, spoke at length of her teenage daughter's excellent progress at school and involvement in extra-curricular activities, as well as her efforts to maintain good communication with her. R4's account of her relationship with her daughter, who now had a good job, and was planning to buy her own flat, was similar. R7 was concerned that her fatigue might adversely affect her children, but also emphasised what she did, within her energy levels, to help them:

when they're in the house I give them all of the attention they want and I do sit and I do read with them and I do do their homework and I try to do all the things that people didnae do with me basically.

Once again, she tied this effort to her concern that her children should have a better life than she had had.

Several respondents, however, emphasised their concern that some of their children, all boys, suffered from behavioural problems, often related to losing their fathers. R10's young son constantly interrupted the interview. She explained he had to be watched constantly because of his fights with other children. Asked, in general, what she found most difficult to cope with about her diagnosis, she focused on this issue:

I find it difficult like finding the energy to keep up with my son, [...] when it's all day and all night. I mean he's getting older and he's not going down til that bit later [...] and I get [...] very ehm agitated [...] There is some days like he won't settle down and he is hyper ehm and I think I want to go to my bed and I can't because with a kid you can't do that... I've got to deal with him.

R1's son also suffered from behavioural problems. Her response to the same question was similar:

I think the hardest thing is keeping to the same hours as my son without having a snooze in the afternoon..umm.. when he goes to school, quite often I'll go back to bed for a couple of hours [...] and in between times I'll go to the shops or whatever [...] pace myself.

She felt the pressure from her son to be a normal mother particularly keenly:

It's scary for him, especially since his Dad died and there's only Mum left and Mum has the same disease as Dad [...] And the older they get, the more they absorb and are aware of when you're feeling down. They're looking for signs that you're not normal, not being normal [....] I've had to try and be normal for the kids. Be there and make the teas, and be there to entertain their pals that are staying over night. [...] Make a good pretence of it, but it's a lot of front.

In spite of these difficulties, both these respondents also emphasised the efforts they made to 'keep up' with their children, trying to ensure that they did not miss out. R10's reaction to my throwaway question, at our second meeting, as to how her son was doing, was perhaps slightly defensive as she enumerated all of her son's different activities. Concerned that she could not relate to a son as well as to a daughter, R1 spoke, at length, of trying to be interested in his mechanical hobbies:

I try hard to be on his level. I've got no ideas about cars, computers, but I'm trying. I'll hold things for him when undoing screws... ask him what bits are.

The respondents' concern to find the energy to keep up with their children's activities therefore provided a further example of their efforts to try to ensure they had a normal childhood, in spite of the difficulties of their situation. As with all of the other issues discussed in the last few sections, this concern further illustrated the respondents' consistent focus on being good mothers to their children, in spite of their difficult circumstances.

Conclusion

Although I did not ask any direct questions relating to motherhood, all the respondents spoke spontaneously and at length of their attempts to be good mothers to their children. This chapter has traced their painstaking efforts to establish a post-

diagnosis identity as a good mother, and highlighted the importance of motherhood to them, as compared with other potential sources of post-diagnosis identity.

Like many parents, the respondents were concerned that their children should have a better life than their own. For these women, however, this concern was intensified by the imperative that their children avoid the mistakes most saw themselves as having made. Similarly, it was important that their children's future should be secure, unlike their own.

Any issues relating to these measures of success or failure were therefore acutely sensitive. Although some children were, as yet, too young for any such judgement to be made as to their future, their mothers were very concerned about their behavioural difficulties. Two respondents' older children had followed similar paths to their parents. While R1 did not see her child's drug use as a reflection on her parenting, R3 did tend to blame herself for her daughter's pregnancy, despite all the advice she had tried to give her.

Several respondents were happy to speak at length of the academic and material achievements of their children. R11 and R2 were very excited by the idea that their daughters, both of whom were doing well at school, could go to university. R4 and R8 were equally proud of their children's white-collar jobs, and the fact that they had bought, or were planning to buy their own properties. All of these matters were seen as evidence of their children's future security.

The respondents' focus on these outcome measures pointed to an underlying fear of the effects of their diagnosis on their children. They also reflected the respondents' acute sensitivity around issues of motherhood. On the one hand, the strong cultural resonance of the institution of motherhood provided a potentially secure source of identity. On the other, the respondents were intensely concerned that for them 'motherhood' might represent a double-edged sword, the notion of the 'good mother' having long been constructed in opposition to images of the 'bad mother'. According to Warner:

the bad mother is always present as an issue, as a threat, as an excuse, as a pleasurable self-justification and as a political argument [1994, 25 in Woodward: 1997, 251].

These respondents were under no illusion as to the difficulty of their establishing and maintaining identities as good mothers, and of the constant need to be vigilant to protect this identity. Many had had first hand experience of contemporary prejudices that HIV-positive mothers cannot be 'fit' mothers, because of the behaviours associated with the transmission of the virus. In particular, whether they had used drugs intravenously or not, several respondents felt tarred with this brush, providing examples of service providers, and others, assuming they used drugs. Moreover, some respondents were acutely sensitive to any incidents in their past, such as previous drug use or involvement with the SWD, which might threaten their identities as good mothers. Current childcare problems were even more difficult to discuss. The respondents' accounts highlighted their engagement in a process of constant risk management, to prevent the fragile edifice of their good motherhood, so carefully constructed, from crumbling away.

Part of this process of resisting threats to their identities as good mothers included emphasising the positive choices they had made to prioritise their children's interests as compared with their own. In particular, most respondents insisted that initiating serious intimate relationships would be incompatible with good motherhood. In addition, many issues discussed by the respondents emphasised their concern for the potential implications of their diagnosis for their children. First and foremost, the respondents emphasised their determination to survive until their youngest child reaches adulthood. So entwined was this desire with their post-diagnosis identities, several respondents found it difficult to conceive of another purpose to their lives. Another crucial concern was to try to balance the ideal of ensuring a normal childhood for their children with the potential implications of their diagnosis. For example, most of the respondents worried about maintaining enough energy to make sure their children participate in normal childhood activities, while wrestling with difficulties related to talking to their children about their diagnosis, and preparing for a motherless, and possibly parentless, future.

The respondents' efforts to be good mothers were therefore central to their post-diagnosis reconstruction of identity. In the next chapter, these findings will be explored in relation to these findings.

Chapter 6: The Relationship between Service Use and the Respondents' Construction of Identity as Good Mothers

The previous chapter highlighted the respondents' concern to establish and maintain identities as good mothers. Their emphasis on motherhood far outweighed other potential sources of identity, such as friendship, partnership and community involvement. The importance of good motherhood to their post-diagnosis self-perception was further underlined by their awareness of, and efforts to guard against, any potential threats to this identity. Many of the respondents' comments also tied the content of good motherhood to the concern to live their lives normally, both for themselves and for their children. In this chapter, I will examine the extent to which service use fitted in with, or threatened, the respondents' identities as good mothers, and their aim of ensuring a normal childhood for their children.

In the first part of this chapter I will explore the respondents' attitudes towards various statutory services, such as hospitals, schools and the Social Work Department (SWD). This will be followed by an examination of the respondents' attitudes towards, and their use of, voluntary sector services for themselves and for their children, including meeting places with crèches and playgroups for children, and relevant counselling services.

Overall, it proved very difficult to disentangle the respondents' service use from that of their children. This partly related to practical requirements, for example crèches while children were young. However, it is also clear that the respondents' concepts of post-diagnosis normality influenced their perceptions of the level of service use compatible with a normal childhood, and, therefore, with their identities as good mothers. Similar narratives of living life normally in spite of the diagnosis translated into different types and levels of service use. The second section of this chapter will explore the often different conceptions of living normally held by respondents who had been diagnosed early in the epidemic, and told their diagnosis was terminal, as compared with those diagnosed more recently. For the latter respondents, a greater level of service use was compatible with living normally and ensuring a normal childhood for their children in spite of their diagnosis.

Attitudes Towards Statutory Children's Services

In this section the respondents' experiences of statutory children's services, such as schools, hospitals and the SWD, will be discussed. I did not incorporate questions relating directly to the first of these two services into my topic guide. As discussed, I wanted to emphasise to the respondents that I was focusing on them as individuals, rather than as mothers. On reflection, I could have circumnavigated this concern by leaving such questions to the end of the interview. Further, the respondents' experiences of agencies which would relate to them primarily as mothers might have provided some interesting insights. In the following sections, therefore, I will briefly discuss the unelicited comments the respondents did make about schools and children's hospital services.

The Respondents' Experiences of Education Authorities

The respondents' main concern with respect to schools related to confidentiality, as discussed later. Helping their children with their schoolwork was also one way that the respondents could illustrate their attentiveness. With respect to the role of schools themselves, however, there were fewer comments.

R9 and R5 were the only respondents who made critical comments. R9 recounted several battles with schools who insisted that her son should be tested for HIV:

[the headmaster] says your son has to be tested. All children have to be tested. And I says well that's crap, nobody has to be tested. All children have to be treated the same.

She wanted to complain but feared that her son would suffer repercussions if she did so.

R5 mentioned another concern discussed by some of the service providers whom I interviewed:

She has difficult times sometimes...at school, say they're discussing [HIV][...] it upsets her. But I've been to the school, told them that she doesnae want to discuss that eh? They've not to make her discuss that because it's difficult for her than it is for the rest of the class [...] because it's in her face every day.

The tenor of other respondents' comments was complimentary or neutral. R1 accepted that her son's school was right to refer him to other services for help with

behavioural problems. R2 appreciated that her daughter's school, aware of her family situation, kept a close eye on her.

In general, however, school was not perceived in the same way as social services. The respondents had little choice but to send their children to school. Going to school seemed so much a part of a normal childhood to them, perhaps, as to be unworthy of comment. To a degree the same may be said of their use of children's medical services.

The Respondents' Use of Children's Medical Services

Some of the respondents, including R2, R3 and R4, were diagnosed after their children were born, and it seemed that the HIV status of their children had never been at issue. For other respondents, however, the earliest example of their use of children's services is that of medical rather than social services, with newborn and young children being monitored for antibodies to HIV.

As recounted in the previous chapter, many respondents' experience of diagnosis, often while pregnant, was appalling. R9, whose situation may have been exacerbated by living in an area with no specialised residential facility, used no services for herself for nine years post-diagnosis. She went to hospital with her son during this period for a while after his birth, but then withdrew from any contact with services for a further three years as a result of the perceived roughness of his treatment. R10 also indicated that she had to be persuaded to go to the City for herself after her baby was born.

In spite of their experience of diagnosis, however, several respondents greatly appreciated the counselling element of their relationship with specialised medical staff, helping them to deal with their fears and concerns relating to their pregnancies and to their children's health.

Two respondents, one initially considering an abortion, were counselled through post-diagnosis pregnancies by sympathetic members of the medical profession, and were very grateful for this. Such advice was likely to be particularly important given the prevailing disapproval of pregnancies of HIV-positive women. R7 described one doctor as:

brilliant. He counselled me through...like the next two months of my pregnancy ...and he kind of reassured me that the bairn might not be positive.

Similarly, R12 recounted:

I went and met this doctor [...] and she told me statistics that only one in four children if you keep yourself healthy, and she more or less took me under her wing, put me in hospital, put me on methadone and kept me healthy.

After birth, most of the children were tested over several years to ascertain whether or not they were HIV-positive. R6, who had rarely used HIV-specific social services, had nothing but praise for the medical staff who had monitored her daughter's progress:

I no longer see them because she's [older] and the [tests]'re still negative [...]but [...] I must say they were brilliant with me when they came to take her blood and stuff and [they] would sound very reassuring and they know everything about everything to do with kids to really put your mind at ease [...]... because I was like a very paranoid mother for obvious reasons [...] when she got ill, or when she got a cold, [...] and they were brilliant.

One respondent seems to have been drawn into using medical services herself, after attending a children's clinic. However, the use of children's medical services, like the women's own use of medical services, does not seem to have generally served as a gateway to any use of social services, either for themselves or their children. Their use was considered to be 'normal' and presented little threat to their identities as good mothers. The same may not be said about the respondents' encounters with the SWD, the subject of the next section.

The Difficulty of Incorporating Use of the SWD Into a 'Normal' Life

As discussed in Chapter 2, the literature in the early 1990s emphasised the concern that HIV-positive mothers would be deterred from using social work services, out of the fear that they would not be considered good enough mothers, and their children would be removed. That this fear was an entirely reasonable one, particularly for women drug users, was highlighted in that chapter, with reference to legal, social research, social work and policy sources.

For example, the London Positively Women survey found that:

a third of the women said that they were concerned that their child[ren] might be taken into care, and these worries may stop them from asking for services and suggesting they cannot cope [1994, 52].

Analysis of the transcripts revealed that the respondents in this study understood these concerns. In fact, the opinions of the SWD, expressed by those who had previously been involved with it, were overwhelmingly negative and visceral, even after many years. Many of the comments below were made in response to my question whether the respondents would advise a newly diagnosed mother to contact the SWD. I later realised that these questions were less hypothetical than I had assumed, since several respondents were involved in advising other women, for example through self-help agencies.

Only two respondents with experience of social workers spoke warmly of them. R8 described the social worker she had when she was using drugs as 'brilliant'. R12 found the social workers who had helped her into a methadone programme 'very supportive', and did not resent their threatening her with losing her child if she did not co-operate.

Most respondents, including R8, however, said they would not advise others to contact the SWD. Several respondents vividly expressed their fear of social workers' statutory powers:

I don't know a good thing about the SWD anyway. [...] I just always had this stigma attached with [them][...] it might have changed now but I never go for the help. In the early days it was always the case that if you were a drug addict you had a good chance of getting your child taken away ..they always had the attitude that if you were a junkie you couldnae bring up your kid right [...]. Well that's a lie because I've been a junkie and I've brought up my kid and doctors and police officers whoever, who've ever came to my house [...] cos I kept it clean, myself respectable, the bairn was always clean and tidy, could never fathom that out that I could do that (R2).

Fear and resentment were also expressed by R3. When asked, as were all respondents, to name those important to her, she emphasised that her list did not include any social workers:

I dinnae have one of them. I had a bad time when I was a drug addict [...]my Mum was ever on the phone constantly getting social workers at my door and I was saying God, my bairns are alright you know [...]I hated them [...] they were constantly harassing me [...]looking in my cupboards to see how much food I had.

R7 was equally bitter:

I hate them [...] Because I was into drugs there was this big meeting, and they were gonnae try and take the bairns off me and, oh God, what a nightmare. [...] I was under this thing for three months..they could come round at any time just to make sure...

She also suspected that a male social worker had abused his position during this period by visiting her late at night, and her response to my first interview flash cards left little room for doubt as to her general opinion of social workers:

[they] want to control your life, bossy, nosey, treat you like child, I don't trust them at all, judgemental, they had judged me before they even met me, just because of what they had read on their files, not child-friendly.

Respondents who had never used drugs shared this fear of social workers. R10 mentioned her anxiety that social work might remove her child, as did R6, who would also not advise a newly diagnosed mother to contact social services:

for somebody's who's been newly diagnosed [...]she has so many paranoid thoughts. [...] The whole guilt thing totally initially ...[...]but the fear of like social work might take that child away..I don't think the social work has got a good name for themselves and maybe that's changing as well [...]I mean I sort of believed at one point that they were going to take her away from me...[...] I was having a hard time, [...] with [partner] ..I thought I had to keep things together you know....and the slightest flaw.

For R1 this concern was current. Her past experience had taught her not to be:

too ready to tell them everything. I had one social worker [...] who was eventually put on the Child Protection Team and she was very judgmental and I felt I'd been too open with her. [...] In subsequent visits [...] I always felt she was looking for the things that were wrong instead of looking for the things that were OK or getting better.

This experience had coloured her current contact with social workers with respect to her son, who was having behavioural difficulties. After living with HIV infection for 12 years, with little help from services, she found this sudden intervention difficult to accept. Her interview contained several very articulate passages, well-honed by talking to journalists and researchers. Her accounts of her current situation,

however, including the SWD's involvement, were in contrast rambling and confused, indicating her discomfort, and suggesting a feeling of being stigmatised:

At the moment they do seem to want to control my life. [My son's] temporarily living elsewhere. I hate that 'in care' phrase...it sounds like I've given him away, but I haven't, we're just having a wee rest from each other.

Her attitude to the SWD was deeply ambivalent. On the one hand, she accepted the basis for their intervention. Further, she used the pronoun 'we' in her accounts of SWD actions, indicating a measure of trust and agreement or perhaps an attempt to convince herself the relationship was a partnership. At the same time, she expressed a feeling of powerlessness with respect to the SWD decision-making process:

all these committees that I don't get to know about, and they have meetings about me and [my child] within their own wee circle and they've got superiors and they've got supervisors [..]I mean the social worker I deal with, she's got a woman above her, and there's a woman above her, and there's a man above her and they have meetings and I don't know what gets said. [...]It's just lots of extra people I don't meet that seem to know and have power of some kind that I'm unaware of.

Her description recalled Hughes' description of the decision-making system as 'Multi-disciplinary Kafka' [1995, 295], despite her own experience as a social worker. R1 seemed to feel overwhelmed by the extent of SWD involvement in her life:

they go too deep [...] it's like they're totally intervening in my life you know.

The transcripts did provide isolated examples of shifts in the attitudes of some respondents towards social workers. R11 and R4 had both recently been allocated social workers, and were very happy with them:

[she] doesn't tell me what to do and what it's like to live with HIV (R11).

Significantly, these workers were from the community care, rather than the children and families, teams. Further, both respondents referred to them as 'community care' rather than 'social' workers. R4 had also waited until her child became an adult before accepting this help. However, the fact that R11 accepted her community care worker, knowing who she worked for, suggests that she did not perceive involvement

with the SWD, at least on this level, to be incompatible with her identity as a good mother.

In conclusion, therefore, half the respondents expressed their fear of social workers' powers in blunt terms, some fiercely criticising the social workers with whom they had had contact. These reactions suggest that social workers still posed a threat to several respondents' identities as mothers.

Although a spokesperson for the Glasgow SWD told me that this fear of social work was not an issue there, this was somewhat contradicted by a Glasgow hospital social worker. In general, as discussed in the literature review, these fears have been recognised by many UK Social Work Departments. In Edinburgh, SWD representatives I interviewed confirmed that recognition of these fears had influenced policy. In particular, it had been decided to fund voluntary social services, with no statutory responsibilities, to provide services to mothers with HIV infection, rather than providing them through the SWD itself.

The remainder of this chapter will focus on the respondents' attitudes towards the use of these non-social work services, and the degree to which they considered that the services available were compatible with ensuring a normal life for themselves and their children, and, thus, with maintaining their identities as good mothers.

Perceptions of Service Use as Incompatible With a Normal Childhood

My interviews with some service providers suggested that some HIV-positive mothers might be drawn into service use out of concern for their children. From my analysis, however, it was difficult to disentangle the respondents' service use for themselves from that for their children, since, for example, it was often impossible for the respondents, most of whom were single parents and some with little contact with their own parents, to use services if no crèche was provided. This is also suggested by the intensity of many respondents' use of services such as playgroups and foster carers for their children. For example, 8/12 respondents had used 'social space' agencies with playgroups; and 5/12 respondents had used an agency providing babysitters and lifts to enable them to use other services, or just to have some time off.

As suggested in the previous chapter, however, six respondents (R1, R2, R3, R4, R5, R6) had used services, both for themselves and for their children, far less frequently than others. Of these women, four had been diagnosed early on in the epidemic, in the mid-1980s, while another, although diagnosed later, was good friends with several of these women.

These respondents' reluctance to use services might be explained in part by a lack of appropriate HIV-specific social services for children in Edinburgh at the time of their diagnosis. Most of the children's services opened post-1990: for example, a major service which provides children's play-schemes in addition to other adult-focused services was set up in 1991, and an agency providing bereavement counselling in 1993. A worker for the latter agency, whom I interviewed, explained:

Originally there was more emphasis on adults with HIV, rather than on children. The assumption (and what happened was) that children would be taken into care and nothing was really worked out for them. It was also thought that a lot of children would die or become ill which has not been the case, or the case for a much lesser proportion than was originally thought.

R5 mentioned that she had been involved in setting up a group for HIV-positive parents and their children because no such services existed, although she herself had never used it. Further, R2 indicated that, when she had tried to find services for her daughter when her father died, those available were inappropriate:

she went there [non-specialist facility] for a few years for counselling after her dad died with bad behaviour and [...] I couldn't even go out anywhere [...] She was terrified because [her dad] went in for a test and died on the 7th day, and she was terrified to let me go. [...] So I used [child psychologist]. [My daughter] had a clash with one of them though [...] and she ended up saying 'Mum, I'm going to deal with this myself. They're too arty-farty for me, draw this picture and draw that picture'.

It may also be significant that, when specific children's services did become available, some of these respondents' children were old enough to have more of a say as to whether or not they wished to attend. The fact that no services were available until R4's child was 16 may, therefore, have been an important influence on her relatively minimal use of services. Their children's ages can only provide a partial explanation for most of these respondents' non-use of services, however.

since in 1993, by which time several services had become available, three of these respondents had children aged under ten.

In my view, a more important influence on these respondents and their children's service use was their perception of the incompatibility of HIV-specific service use with their aim of enabling their children to lead a normal life. These six respondents, at least for a significant period post-diagnosis, found the use of HIV-specific services more difficult to reconcile with their self-perception of continuing as normal in spite of their diagnosis. Use of these services could not be considered normal behaviour, either for themselves or for their children, nor compatible with good motherhood. In the following sections, some of the ways in which this concern was expressed will be examined.

Concerns for Confidentiality Related to the Integration of Social Service Use Into Normal Life

Several respondents in this group of non-users of children's and other social services spoke of their emphasis on confidentiality when their children were younger. This concern had often led to the avoidance of service use, both for themselves and for their children.

Part of this concern to maintain confidentiality may have related to avoiding SWD scrutiny, since several of these respondents were using drugs at this time. Another related factor may be that, as some of these 'early diagnosed' women asserted, discrimination towards people with HIV infection was much greater in the mid-1980s than now. This was expressed very strongly by R3, whose friends had rejected her on diagnosis, and R4, who had been thrown out of the family home. These respondents wished to protect their children from being stigmatised as a result of their own illness. R2's and R4's children had in fact been bullied for this reason. These factors are not determinative, since many women who now use services also experienced prejudice, but they seem to have influenced some respondents' early attitudes towards service use.

Being bullied or stigmatised may often originate in considering others to be different in some way. Several respondents were also concerned that their children should not feel themselves to be different. They wanted to preserve their children's understanding of their lives as normal. R4's explanation for her previous emphasis on maintaining confidentiality reflects this:

I know when my daughter was young.... I didn't want people knowing because I didn't want them to make her different from other kids.

R3's description of her reaction to her diagnosis also suggests that focusing on her diagnosis, for example, would not be compatible with her all-important aim of ensuring a normal life for her children:

My theory at that time was that if I'd a job, it'd take my mind off that and I'd be able to live normally...get the kids a normal life you know, that was the most important thing all they years ago.

Perceptions of the Compatibility of Disclosure and Ensuring a Normal Life for Children

Another problem for some respondents, with respect to integrating service use into a 'normal life' for themselves and for their children, was the emphasis of some service providers on informing children of their parents' diagnosis as early as possible. For several respondents in this group of 'service non-users' such information could only shatter the normal childhood they put so much effort into preserving for their children.

The service providers I interviewed also expressed different opinions on this issue. Most child-focused services, such as the SWD and a bereavement counselling agency for children, emphasised the importance of discussing the diagnosis with children, and on obtaining bereavement counselling for them where appropriate. In contrast, a worker at a self-help agency criticised this emphasis on disclosure, stating that parents knew best when to tell their children. Another agency provided a playgroup for children some of whom knew their mother's diagnosis, but others did not, while an agency providing practical help did not engage with this issue at all.

Respondents who did not wish to disclose their diagnosis to their children could discriminate between the approach of each service, using those which least threatened their conception of normality. This may help to explain the very widespread use of the agency providing practical help. The worker I interviewed from this agency described its function as helping the respondents to live 'normal' lives. Like some of the respondents, therefore, she used the word 'normal' to indicate minimal or no use of HIV-specific services.

Use of the more interactive, child-focused services was influenced by the respondents' philosophies concerning the compatibility of disclosure with 'living a

normal life'. Of the group of five women who had used fewer services for themselves or their children, R2 and R4's children learnt of their mother's diagnosis almost by accident, between the ages of 8 and 10, and had received little or no counselling. For R2 this reflected a time in which she had told virtually no-one of her diagnosis:

I wouldnae advise them to tell the kids they were HIV unless they were announcing it to everybody else ... you can't say [when] that's somebody's personal decision at what age you tell them.

R3's children had not learnt of her diagnosis until late in their teenage years, when they were told by her estranged ex-partner. Her opinion was that, as long as she remained healthy, it was better not to tell, and, therefore, not to worry her children. She also did not consider they should receive counselling once they had been told:

I feel that if I can say to my kids [...] 'I have got AIDS pal but I'm OK, [..]and when I'm no, I'll tell you, so dinnae worry, I'm gonnae be around for a long time you know'. [...] I think personally that is enough counselling, ken because everybody's parent dies, we all die and it's just the way we look at it you know, I think. Maybe I'm wrong for my children, [...] but [...] I find the people at the top, who are nae positive, have no got that understanding because [...] a lot of people tell their kids when they're young.

Her comments focused on a concern to convince her children that their situation was 'normal' despite her illness. They also suggest that she felt pressured by the prevailing ethos of disclosure. To help her children, after they learnt of the diagnosis, she tried to find them work with HIV-positive people, hoping that this would convince them that HIV-positive people are normal:

and [to] see that these people arenae dying either you know, we're all happy, we're alright and if we're gonnae die, we're gonnae die, you know.

Her son had, however, subsequently become involved in a group for and run by older children of HIV-positive parents which will be discussed later in this chapter.

Criticism of Certain Services As Part of a Narrative of Transformation

In previous chapters, I discussed how some respondents' narratives of living a normal life in general, and being a 'normal' mother in particular, had emphasised the huge changes they had made in their lives since coming off street drugs. The effects

on their children of their own and their children's service use also formed part of this narrative.

Several of these respondents criticised a residential respite facility on the grounds that other residents were often high on drugs, and that this service was not, therefore, suitable for children. This complaint was most frequently made by women who had previously been addicted to opiates. R2's comments drew on the past when her now mature daughter was much younger, but were nonetheless employed to explain her current non-use of this service:

I was shown round it once [...]. I was contemplating going in, taking [child] but it wasn't until I actually saw the drug addicts lying about like out of their heads and I thought [child] doesnae need to see this [...] Fine if they're on drugs, nothing against it, but I don't need my child seeing that. She's seen stuff in her early years. In the last seven years it's been a big change from like the drugs years to straight living, even paying the TV licence, ken [...] back to normality again and I like it that way.

In R3's second interview it was her son who brought up this concern. She remarked:

It must be quite frightening for someone with kids, [...] going in there for the first time and seeing that ..cannae even lift their heads up and slavering at the mouth [..] If you were younger, you would say 'oh that must be because he's got AIDS', no realising that it's actually drugs.

These respondents' concerns to ensure a normal childhood for their children were, therefore, an important influence on their own and their children's service use. In particular, these respondents did not consider service use to be compatible with a normal childhood, just as they did not, in general, consider service use to be compatible with their aim of getting on with life post-diagnosis.

In contrast, however, several of the remaining respondents indicated that they perceived services, including the same residential respite facility, to form part of their plans to ensure a normal childhood for their children. In the following sections, the ways in which these respondents integrated service use into their narrative of providing a normal childhood for their children will be explored.

Perceptions of Service Use As Compatible With A Normal Childhood

Unlike the six respondents whose views were examined in the first part of this chapter, the remaining respondents emphasised the importance of children's services. Like the first group of respondents, they highlighted the importance of living a normal life and of ensuring a normal childhood for their children, but presented a very different idea of the content of ensuring a normal childhood for their children from that explored above. In particular, they felt that services could not only be 'normalised', but could even help to ensure that they lived a 'normal' life. Again, the perception of what was normal for their children seemed to reflect what they considered normal for themselves, since, over time, these respondents had used more services for themselves than those whose views were analysed in the first part of this chapter.

Making Sure the Children Do Not Miss Out

As discussed, many respondents were concerned that they lacked sufficient energy to ensure their children participated in 'normal' childhood activities, without their own health being affected. Several of these respondents were very appreciative of services, such as playgroups and foster care, that could help their children engage in such activities without their supervision.

R7 greatly appreciated a social space agency's play-scheme for this reason:

It's brilliant...they've got clubs and swimming nights and weekends every other weekend a play-scheme on a Saturday or a Sunday and they're away for about 10 til 4pm. It's good.

She was also happy that the agency's workers pushed her to do things with her children, and considered that these interventions helped her to be a better mother:

I mean I would never do anything in my life if they didn't push me [...] there's actually two people in here. [...] Sometimes I lose it with them [...] because they're always on the phone, like 'come on, do this, do that', I'm like 'oh!!!!....' But it's good [...] and I says to them. 'No yous have to do that wi me. Just keep nipping' [...] I'm not a perfect mother [...] Somebody has to push me to take them swimming or to do this.

R1, who had only recently started to use services, was hoping that a buddy could be arranged for her son to participate in activities she found too draining:

we're trying to set up a [...] buddy [...] a male role model to go go-kart racing etc all these things I just don't have the energy to do. I've got the enthusiasm but [...]by the time I get to a bus-stop I'm exhausted, and to stand around at a speedway freezing [...] I think it's better if he's got his own person to do that sort of thing [...] And we're in the process of having respite care for him, you know, one weekend a month where he can go and be [...] a boy doing boy things because with it just being me and himself round the house, he's down-hearted, he mooches around and it must be awful.

Further, while wary of the fact that her son had recently spent a short period with foster carers, she also appreciated the opportunity it had given her to 're-charge [her] batteries'. She also thought that this period had helped him to understand that many aspects of his home life were in fact 'normal,' despite her condition. Prior to his experience of foster care, she felt he had rebelled against her discipline as he felt that her strictures were associated with her HIV-infection and not with a normal life:

it was his way to get me to be a normal mum in a situation that is not normal [...]but over the last few weeks, he's been in care [...] and [...] he's had some time out to see what it's like with other [...] [families]...and it's normal to tidy up your bedroom, it's normal to take your dirty clothes and put them in the washing basket [...] And I'm not being over-demanding [...] these basic rules are important in other people's houses.

R1 also appreciated the residential respite, which she used for 1-2 weeks at a time, two or three times a year. She described it as child-friendly in the main. Although her son had clashed with one of the workers, it provided him with a further opportunity to behave like a normal young boy:

I appreciate the respite and so does my son. Because when he's there he knows Mum's safe and he can be a wee boy, he can run around the trees and whatever and he knows that he [...] can be a child as opposed to a child-carer.

R11 found that a fortnight was too long a stay for a parent, so she usually arranged to stay for a week only, while her children stayed with foster or her own parents. She also appreciated this service because:

It gives me time off, a week when I can say I'm, I'm not a mummy, I'm me

Although there were some individualised problems, as well as a concern that these services did not provide adequate feedback, several other women (R8, R9, R10, R12) spoke in glowing terms of play-schemes as well as foster parents and other types of respite care. In total, about half of the women interviewed had used children's services in part as a means of compensating their children for their lack of energy, while maintaining their own health. These services, therefore, helped the respondents deal with one of their major concerns relating to being a good mother. In assisting the respondents to provide a more 'normal' childhood for their children, these services were compatible with their narratives of good motherhood.

Use of Services to Help With Telling Their Children About Their Diagnosis

Some respondents also used children's services, including a playgroup and a bereavement counselling service, to help them to disclose their diagnosis to their children, and to deal with some of their children's subsequent anxieties and questions. The latter service also provides specialised bereavement counselling for children who had lost, or were likely to lose, their parents [also see Morton and Johnson: 1996].

Four respondents had disclosed their diagnosis to their children at a young age with the help of a counsellor from the bereavement counselling agency who continued to work with them. R11, for example, had told her children while aged under eight with the help of a counsellor who ascertained what each child already knew or suspected, and gradually built on this knowledge. This agency was also used by R7, R9 and R10, while R6 was considering using it.

This work was very sensitive and was greatly appreciated by these respondents, in that several of their children had lost their fathers to AIDS, and appreciated the gravity of the information, despite their young age. R10 commented:

She was very upset, I was upset, so that's when I got in touch with them. It's all come out since her dad's death.. the build up of all that. And she was very upset.. more than we all realised. So...[a counsellor]'s coming every fortnight and [she] loves seeing her, she's very comfortable with her.

She appreciated the flexibility of this service, calling them when 'she's quite hyper and got things bothering her'. R11 also enthused:

She [counsellor] does wonders with my bairn [...] it takes the stress out of motherhood.

R7 thought her children had come to consider their counsellor as their grandmother.

R10 also appreciated the play-groups which, similarly, did 'the serious work about HIV'. She had been concerned that her son did not enjoy his sessions there but he had reassured her to the contrary. She thought he enjoyed the group for reasons similar to those for which she enjoyed her own use of groups:

he knows once he goes into [two play-groups], and it's the same when I go in, he knows wow this is great, you can relax and talk about HIV, everybody's in the same boat one way or another and I think [he] feels that as well which is good for the kids.

At these specialised playgroups, she felt he could relax, talk about HIV and escape from everyday life in which he is discouraged from talking about his mother's condition. In her opinion, therefore, using these play-groups helped him to feel 'normal' in spite of HIV, by providing a space in which he could feel the same as everyone else. The association between the use of services and providing a measure of normality for their children, in spite of HIV infection, is clear in these comments.

Use of Services to Help With Preparation for the Future

In the previous chapter, I discussed the idea that part of being a good mother involved preparing children for the possibility of their mother's mortality. For the respondents whose attitudes were explored in the first part of this chapter, this concern was approached in terms of teaching their children to be independent in the event of their deaths. Several other respondents however used services to obtain psychological and practical assistance, for themselves and their children, to prepare for illness and death.

R12, for example, described how her social worker had helped her to make:

a wee video of [daughter] of me talking to [daughter] for her to take when I'm dead, it's a good idea [...] She'll always have it.

This type of work was also carried out by the bereavement counsellors mentioned above.

Most of the agencies provided help with arranging wills to determine who, whether a family member or the local authority, should look after their children should they die.

Four respondents used foster parents for respite purposes. Some respondents, however, also saw their use of respite services as part of their plans for their children's future. R10 had reservations about using the residential respite facility herself. She felt that she could not rely on her family to provide childcare during the usual two-week period offered. She was worried about taking her child to stay with her there:

her dad was in there for a year [...] and she was really hyper. [...] She's just so loud and just like jumping about chairs and settees and things. And I think, what if she does all that?

Despite these reservations, however, R10 did not want to lose touch with this agency for her child's sake. She made sure she used the playgroup there:

I feel [...] I could be in there .. for respite or terminal in the future, hopefully not for a long time, but I think it's important not to keep her away from the building. [...] If my time comes.. it'll be as well if she's comfortable with the place, it won't be strange, the staff won't be strange to her ehm. I think that's really important for me [...] She's quite comfortable talking to [worker], he knows it's safe to talk about myself and her dad.

R11 had fought a long, difficult battle with the SWD for her son's relationship with his foster carers to become permanent should she die. The worker from the bereavement counselling agency I interviewed explained:

One of the things that mothers want is for respite care to lead into permanency. For example, respite carers gradually taking over. This is tricky and expensive to organise, partly because of the nature of the illness. Mothers may need respite care once every two months gradually taking over. Mothers want to know who will be caring for their child, unlike their present uncertainty. But it is difficult to find families who will do this and expensive. It doesn't fit with the way the Social Work Department and adoption services have been organised, that is as respite care as something separate from adoption.

Several of the other social service providers I interviewed also identified this as a problem, including two representatives of the SWD. They emphasised the lack of funds to advertise for foster parents and to pay them retainers to ensure consistency for the children.

By the second interview, R11 had achieved her aim. Her son was getting to know his new permanent foster carers, and she was in the process of making a will. It was clear, however, that this issue had been an enormous strain for her. While initially difficult to consider the subject of mortality in terms of ensuring a 'normal' childhood, this seemed to be exactly R11's intention. She wanted her son to be aware of the possibility of her death, but also to have the certainty of knowing his foster parents would take over should she die, and the reassurance of being as familiar with his foster parents and their surroundings as possible. In a sense, she wanted to ensure that, through his spending every other weekend with his foster parents, that he would consider going to live with them normal.

The second part of this chapter, therefore, has illustrated the existence of different perceptions of the extent to which social service use could be integrated into a narrative of ensuring a normal life for their children. There were also indications that the respondents' narratives could shift over time in response to changing circumstances. R1, for example, had been forced to re-evaluate her views by recent events. Although ambivalent about their use, she did appreciate that services could help her deal with some of her concerns relating to ensuring a normal childhood for her child. In the following section, I examine suggestions that the attitudes of the core group of non-users might also change, or be re-worked with respect to older children.

Older Children: Changing Attitudes Towards Service Use

An issue raised by several respondents, including those who had not considered service use compatible with a normal childhood, was the need of older children for services, and the perceived lack of such services. Several service providers I interviewed also pointed to the difficulties experienced by clients' older children:

we're seeing children and not only of the mothers, but of the fathers as well, who are presenting with severe emotional disturbance and .. it's almost like history repeating itself. Kids who are now on scripts, we've got 16 and 17 year olds who are pregnant.

Some of the respondents' children had experienced some of these problems. Even in their absence, however, several respondents were concerned at this gap in service provision. R11's children, now approaching teenage, had been excluded from a holiday play-scheme by one agency on the basis that they were too old. She was very concerned, since in her view her children still required this type of support. They had also been upset by this and R11 was worried that one of her children, who had had no contact with their father, would view this situation as another rejection.

Interestingly, most of the respondents who mentioned problems in service provision for older children were those whose children were in their late teenage or early twenties and who had never, or rarely used, any services for themselves or for their children. To some extent, therefore, this concern might reflect something of a change of heart. In general, however, this was presented as a response to recent concerns, or in relation to the specific needs of older children.

In both of her interviews, R4 emphasised her concern that her daughter, now in her twenties, should obtain some support:

I've had it 15 years like ... so she's lived through all of it with me [...] I think actually she's finding it harder now than she did when she was younger [Why's that?] I dunno what .. but her father died six year ago, my brother-in-law died last year and I think because they didnae really expect me to live as long you know.

She associated her daughter's difficulties, therefore, with recent bereavement and had come to the conclusion that her daughter should now receive some counselling:

I think the older she's getting the harder she's finding it with me being unwell... [...] In the past I've mentioned it umpteen different times [...] and she's always said 'no I've got you'. [...] I'm gonnae talk to [counsellor]. Maybe one day when she's here, you know, not making it obvious but [...] really getting [daughter] to open and say maybe I could do with a pal, a buddy or something.

Although not presented as such, R4's change of perspective may have been influenced by her own very recent use of a SWD counsellor, and her own preference for one-to-one help. R4 had discussed this issue with her own counsellor, but had not investigated how her daughter might obtain counselling. This professional help would supplement the support she received from two cousins of a similar age, one of whose fathers had died from AIDS-related illnesses, and the other from the effects of alcohol dependency.

R2 was also worried by her daughter's strong reaction to her recent illnesses:

I did notice a bit of a rash but I didnae think anything of it. But [daughter] went absolutely hysterical in the office, roaring and crying, 'please phone [consultant] please, please'.

She also highlighted the emotional problems of a teenage nephew:

The only person he relates to is [daughter] because of losing [her father]. And he's lost mum [..]. But she copes with it a lot better.

Recent concerns for her daughter were an important influence on R2's decision to become involved with a self-help HIV agency for the first time in the many years since her diagnosis. Her daughter and R3's son had become involved in obtaining funding for and setting up a support group for older children within this agency. R2 recounted how both her daughter and nephew had benefited greatly from this group set up for young people aged 15 to 18. She emphasised that the group was not all 'sadness'. Although 'safer sex' was emphasised, there was also money for members to go on trips. Both respondents appreciated the format of this nascent group which, like R4, reflected the type of service use with which they had recently become involved.

Conclusion

In this chapter, the influence on service use of the importance to the respondents' identities of being, and being seen to be, good mothers has been explored. Graham [1984] analysed the role played by mothers as mediators or gatekeepers in relation to the service use of their children. In this chapter, I have examined an important influence on the exercise of this gate-keeping role: their conception of how to live as normal mothers, and to ensure a normal childhood for their children.

For six respondents, most of whom were diagnosed relatively early in the Edinburgh epidemic, service use tended to be considered incompatible with this aim of ensuring a normal childhood for their children. For example, several respondents were concerned that service use would 'mark out' their children in some way, making them more vulnerable both to bullying and to feeling that they were different in some way. Several of these respondents had also felt reluctant to disclose their diagnosis to their children, on the basis that this information would shatter their children's sense of living a normal life. Interestingly, this conception of normality was shared

by some service providers who did not view the use of their own services as compatible with living a normal life. One, working for the children's bereavement counselling service, told me:

people don't want to think of themselves as being ill. And our activities obviously make them aware of the other side of things, of the worries they want to protect themselves from. They want to live their lives normally.

In contrast, the remaining respondents had developed ways of fitting children's services into a narrative of living normally in spite of their diagnosis, and of ensuring a normal childhood for their children. For example, some services were seen as providing spaces in which their children could act 'normally', talking unguardedly with other children in family situations similar to their own. Some children's services were perceived as a means of reconciling potentially contradictory concerns that, on the one hand, their children should not miss out on normal childhood activities, but, on the other, that they should maintain their own health and survive until their children reached adulthood. The comments of this second group of respondents, therefore, indicate the extent to which service use, even where directly related to helping a child cope with bereavement, could be incorporated into a 'normal' childhood.

In Chapter Four I discussed how respondents had re-negotiated the meanings attached to specific services, over time, in order to use them. Comments made by several of the first respondents as to the lack of services for older children might be interpreted in this way. Certainly, there seemed to be a connection between the types of service use these respondents had come to appreciate and their views on services for their now adult children. These comments also highlighted a gap in service provision for young people, particularly those aged over sixteen, a finding discussed further in the conclusion to this thesis.

In the next chapter, another important element of the respondents' post-diagnosis identity will be discussed: the relationship between their identity and the different sources from which they received help.

Chapter 7: Continuity Between Informal and ‘Formal’ Caring Relationships and the Respondents’ Post-Diagnosis Identities

In the previous substantive chapters, I have focused broadly on the respondents’ concerns at diagnosis, and the effects of these issues on their post-diagnosis renegotiation of identity, both initially and over time. This chapter will move on, chronologically, to examine the respondents’ often long-term relationships with those providing them with help, whatever its source.

Much of the literature on different sources of care, particularly on the voluntary sector, does not focus on the content of, or values underpinning, relationships between givers and receivers of assistance. Instead, writers have focused on categorising services in terms of structure and source of funding [see Deakin: 1998]. The main exception to this is informal care. According to Ungerson, informal care is understood to draw on the love, duty, shared biography and reciprocity, often assumed to inhere in relationships of kinship and friendship [1998, 169; Bibbings: 1998; Heaton: 1999].

In this study, analysis revealed that the respondents’ evident appreciation of informal care from family and friends was often based on these values, and others, such as trust and a concern for equality. These values were also supportive of the respondents’ identities as independent individuals, continuing to live normally in spite of their diagnosis. Only rarely, however, were resources such as emotional and informational support available from within these existing relationships. To bridge this gap, most respondents developed new relationships, of varying degrees of closeness, with other HIV-positive people, often through their use of social services. Reading through their accounts of the genesis of many new supportive relationships, it was often difficult to disentangle informal from other, ‘formal’ supports. On the basis of these findings, it will be argued that, in the context of chronic illnesses, the concept of informal support should be extended to cover new, as well as existing, relationships. It will also be contended that conventional categorisations of sectors of care do not map onto the way that service users think of the relationships between

services, and, similarly, do not reflect the significance of care provision to the respondents' identities.

Further, the relationships with statutory and voluntary sector workers most appreciated by the respondents were constructed upon similar values to those associated with informal care. Most notably, these relationships were sometimes based on shared biography, often sustained over time, and incorporated trust, reciprocity and a measure of equality. As such, they provided support for the respondents' identities as people living normally in spite of their diagnosis. It will be argued that, in the context of chronic illnesses, such issues were much more important to the respondents than conventional conceptualisations of worker or professional-client relationships.

Characterisation of Informal Care in Research and Policy Documents

Informal care has been the subject of much recent attention from researchers and government policy-makers:

Following their emergence in the 1970s, it was only in the 1980s and 1990s that individuals, usually family members, who provide unpaid assistance for their dependent relatives living in the community, became widely recognised and defined by a discourse of informal care [Heaton: 1999, 759; also see Davies and Robb: 1998].

In contrast with other sources of care, in the voluntary or professional sectors, informal care is generally discussed in terms of core values inherent in the relationships with which it is associated. Ungerson, for example makes the following distinction between the voluntary sector and informal care:

the term [informal care] does not normally include volunteers, and this is because the other central feature of the informal sector is that the people who provide the services normally have had a relationship of some kind with the person they are providing services for. It is precisely because of this relationship that they are willing to look after the dependent person. Thus members of the same family may feel they want to look after someone because they love him or her, or they feel that

being part of the same family means that they are subject to a particular set of moral obligations to care[...] In short, the informal sector is based on non-monetary 'ties that bind' such as *love, duty, shared biography and reciprocity* [includes quotation from Finch: 1989, 1998, 169, emphasis added].

Similarly, Bibbings emphasises that:

'informal caring' takes place within an *existing* relationship unlike other forms of care [1998, 171, emphasis added].

Informal care is therefore associated with values such as love and reciprocity, on the basis of which a chronically ill person's family and friendship relationships are assumed to have developed prior to their illness. Other cultural values underpinning informal care, identified by Bibbings, include the concern to maintain 'independence' from services, and to keep matters within the family [1999, 178].

In the context of community care policies, government documents associate 'informal care' with 'normality':

[Informal care] will continue to be the primary means by which people are enabled to live normal lives in community settings [Griffiths Report: 1988, 5, para 3.2 in Heaton: 1999, 765].

Policy documents have also presented the kinship, friendship and neighbourhood ties underpinning informal care as:

irreplaceable. It is the role of public authorities to sustain and, where necessary, develop –but never displace– such support and care [Growing Older: 1981 London: 3, para 1.9 in Heaton: 1999: 761].

In the following sections, the respondents' own attitudes towards, and characterisations of, informal care will be examined in light of the values associated with informal care by Ungerson and others above.

The Respondents' Preference for Help From Informal Sources

The transcripts indicated a very strong preference for, and appreciation of, informal care from family and friends. This was suggested by the lists of 'important people' I asked the respondents to draw up in their first interview, and to reconsider in their second interview. All of the respondents listed more informal than 'formal' sources of help, and the importance of support from family and friends was emphasised by all but two respondents. Of the family members specified, eight respondents mentioned their mothers, eight mentioned siblings, and two their fathers. Unlike the gay men in some surveys, [McCann & Wadsworth: 1992; Hull-York Research Team: 1993], fewer friends than family members were listed. For reasons which will become apparent, the following sections will be divided between HIV-negative and HIV-positive sources of support.

Reasons for the Respondents' Emphasis on Informal Support From HIV-Negative Friends and Family

The Practical Significance of the Support Received

The respondents emphasised the substantial practical assistance they received, often from their mothers, particularly with looking after small children. For example, R10's sister looked after her son for many hours per week. R11's parents and R5's mother had been the prime caregivers for at least one of their children, while R12's mother was becoming her grandchild's main caregiver as she faced severe illness. She recognised this in a poignant tribute:

The most important person, I really hope I die before my mother because I could not live without [her]. She is so supportive, she's been there from day one. I love her dearly.

R5 described her mother 'as like my friend and my sister', the first person she would talk to in a crisis. She wanted her mother to care for her during any potentially terminal illness.

R2 stressed that her family had always been supportive and had never ‘shunned’ her. A sister had looked after her during a period of severe depression. She also emphasised the regular practical support she received from a brother:

my brother A’s my carer. [...]Anything needed done, he’ll be in [...]. Brings the bairns. I just sit and play with [them] and they do all the work. And it’s fun, it’s good cos you’re getting to see the family, but everything’s getting done at the same time.

R7 emphasised the help her HIV-negative partner had given her, over the course of their long relationship, with housework, cooking, looking after their children and helping her off drugs. R3’s and R6’s accounts also pointed to various types of practical support from family members:

Well my sister comes in at weekends and does all my washing, it’s brilliant ..hangs it all up and dries it. And my son, he does a lot of the work for me now anyway because he cooks and tidies up. He’s quite good’ (R3).

The Relationship Between the Respondents’ Post-Diagnosis Identity and the Values Underpinning Informal Care

The respondents’ downplaying of the importance of ‘formal’ help was evident from a comparison between their ‘lists of important people’ and their responses to other questions. In spite of consistent prompting as to whether any workers should be included on their lists, R6 did not include a counsellor she mentioned elsewhere as very important to her. R7 omitted a social worker she later described as a family member, and R3 firmly rejected any suggestion that a worker should appear on her list.

R12’s conceptualisation of the help she received from her mother, homehelp and community nurse as forming part of the same network was exceptional. However, even she was concerned to emphasise the help she received from her family over that received from workers. After her mother, her first inclination was to mention her social worker’s name, but then she caught herself:

well before then my father, my sisters and my brothers and then E [social worker], C, just the people I've known for 10 years being in and out of the ward. [She then listed many specialised hospital staff, doctors, social workers and nurses].

It seemed, therefore, that the respondents preferred to associate the word 'important' with their families and friends, rather than with any other sources of support. Similarly, the Positively Women survey observes that early mistrust of professionals tended to be emphasised over bad treatment in women's personal lives by friends and family [1994, 9].

The reasons for this preference seemed to lie partly in the associations of informal care with shared biography and with 'normal' family relationships. By emphasising the role of their families in their care, the respondents could emphasise their identities as people living normally in spite of their diagnosis. Several respondents, including R3, R4, R6, R11 and R12, had become reconciled with their families after years of estrangement. R12 spoke of the difficulty of regaining her family's trust after stealing from them to support a drug habit. R4 relished the fact that, after having no contact until two years prior to her interview, she now helped look after her niece, and that a sister asked for her advice. For these respondents, the existence of such informal supports further exemplified how far they had moved away from their past to live normal lives.

The respondents' accounts also confirmed the importance of other values identified by Ungerson [1998] as underpinning informal caring relationships. For example, they were particularly concerned to emphasise the reciprocity in these relationships, and that they, too, were carers, as mothers or for others. This recalls Morris' criticisms of early feminist work on caring which downplayed the perspectives of the 'cared for' and ignored the caring work they carry out:

Feminist researchers on 'informal care' concentrated almost solely on the experience of those women they called 'carers', constructing an analysis which allowed no room for the subjective reality of those who are cared for [1998, 163].

By emphasising these elements in their existing relationships with family members, the respondents could also underline their identities as independent people, not only

recipients of help, but also caregivers. For example, they could point out that, although they were not working, they were able to contribute to society. R2 emphasised her own contributions to a family ethic of mutual exchange:

I think it comes from being [...], dead family-orientated [...] cos if it was them, I'd be there so I just expect it back because that's the way that we've been brought up [...] I've got so many of them, I feel like no they should be, cos I've done it, even at the beginning of my positiveness when I was first diagnosed, I used to look after my dad.

Similarly, several other respondents emphasised how they were, or had been, the primary carers for other HIV-positive family members. Nine respondents had had at least one HIV-positive partner, seven of whom had been nursed by the respondents before their deaths. R7's account of how she and her partner had cared for a brother who had died of AIDS illustrated the demanding nature of this work:

most of the time he was constantly in the house and I just felt someone has to be [there] all the time because his legs had run down before he died, so he couldnae get up to make himself a cup of tea [...]. And sometimes I was just so knackered. [...] There was some days [...], because [partner] worked, and I was on my own, and I used to think oh God, I wish there was someone I could call and say will you come for an hour and [...] And sometimes I lost it and would end up shouting at him, [...] if he wanted something, he wanted it right there [..]. And sometimes I used to think 'aaagh, I'll strangle him' [laughs].

Several respondents also highlighted their efforts to avoid overburdening relatives who provided them with support. Asked whether she could talk to friends or family about her problems, R2 replied:

Yes, [...] but sometimes I feel that I dinnae want to go to my family because they're suffering, as well, cos they're affected by my infection.

Although often exhausted, R10 was concerned not to ask for any further help from her sister and parents with looking after her son. She wanted her sister to 'get on with her own life' and worried about the effect of extra work on her ageing parents:

my mum and dad are basically great for their age, though my Dad has had bad health, and the school's a bit away from their house [...]it's a bit much for them to get up in the morning and deal with him and getting him to school, and watch him in the house.

This problem of relying on ageing grandparents was also mentioned by some of the service providers whom I interviewed.

The respondents' accounts, therefore, rejected the notion of 'dependence' implicit in the idea of being a recipient of care. This insistence recalled Morris' concern that:

care users should not be constructed as dependent people [1998, 163; also see Bibbings: 1998, 163].

Similarly, the respondents interviewed by the Hull-York Research Team [1993] rejected the connotation of dependence contained in the word 'care', preferring an idea of informal 'support'.

For some respondents, 'dependence' was particularly associated with professionals. R3's marked preference for informal care seemed to relate to the lesser hierarchy associated with such relationships. Similarly, R5 saw informal care as a means of keeping control over her medical treatment.

The Respondents' Reluctance to Highlight Certain Problems With Informal Support

The respondents' preference for informal support was further underlined by their reluctance to highlight difficulties associated with this source of support.

One such problem, which was not emphasised by the respondents, was the lack of support from some family members. As mentioned, several respondents, including R4, R8, R1, R6, had experienced rejection by members of their families and friends, for various reasons, including drug use, teenage pregnancy and their diagnoses. Even prior to this, family difficulties may have contributed to respondents' drug use [Barlow: 1992]. During this time, no family support had been forthcoming, and some respondents, including R7, still felt stigmatised by some members of their families:

I've never actually says to my dad or my eldest brother [that I am HIV-positive]. When he used to come and see [late brother], [my brother] wouldnae drink out the cups in the house, and this was only, well four years ago now. [...] And when [he] used to come and visit him, once in a blue moon, [...] he'd go to the chippy and get a fish supper [...] wouldn't even take a plate out of my house so [...] I wasnae going to tell him [...] I dinnae have much to do with him.

This issue was a difficult one for some of the respondents to discuss because it detracted from their self-perception of living a normal life in spite of their infection. The same was true of another major problem with informal support, one touched on by Hughes [1995, 307], its unreliability.

R1's interview provided an isolated, but catastrophic, example of the breakdown of a support network, which might have resulted from overburdening. R1 had been helped, for many years, by a teenage daughter and a neighbour, both of whom had abruptly withdrawn this support, amid bitter recriminations:

[It's] a complete dissipation of what I thought I had as a support network round me, and now I'm having to rebuild all that [...] I mean my daughter [...] was down all the time- [...]. From lunchtime to teatime, I had someone to talk to. My next-door neighbour popping in and out. And now they don't do that. It's such a dramatic change. I'm now having to ask professional people to step in there and I didn't need to before. It's bizarre.

R1's interview also suggests that her new reliance on professional help, rather than informal supports, detracted from her identity of living a normal life in spite of her diagnosis, and pointed to a strong sense of loss of 'normal' family connections. These events further reinforced her fear of overburdening her one remaining close friend, whom she now avoided calling at weekends, to give her a break.

Equally revealing, however, was the reluctance of the other respondents to highlight any lack of reliability in the practical support provided by their HIV-negative family and friends. This observation further underlines the importance to the respondents' post-diagnosis narrative of continuing to live normally in spite of their diagnosis.

The Achilles Heel of Informal Support From HIV-Negative Family Members: Lack of Emotional Support

The respondents' preference for informal support remained intact in spite of these potential difficulties. The fact that the respondents were prepared to emphasise the difficulties involved in relying on this group for emotional support suggested that HIV-negative family and friends were not perceived to be the preferred or a reliable source of emotional support.

For example, R7, whose partner was exceptionally helpful in practical terms, pointed to the lack of emotional support as one of the major spurs to her contacting service agencies after a long period, post-diagnosis, of not using services:

For 12 years [...] I never spoke to anybody about the virus, except my partner. And [...] I told him, and it was like he never spoke to me about it again.....until my brother became quite ill.[...] I'm the one now that brings up things. [...] I want things to get sorted out, [...] arrange my own funeral, just make sure everything's alright, ehm. [...] And I say things like that to my partner but he doesnae want to hear things like that, he's like, 'oh God, we've got plenty of time for things like that, plenty of time' (R7).

R3 also mentioned this problem. Many other respondents' family members, while happy to provide practical support, also found the respondents' diagnoses difficult to accept or discuss. R2's, R5's and R12's accounts of a high level of emotional support from family members were unusual, as were R2's, R6's, R8's, and R10's accounts of the emotional support they received from HIV-negative friends.

More typical were R6's difficulties with her mother's denial of her diagnosis:

[she] only found out last year [...] and she's went into denial about it and [...] I'm not making it like headline and stuff, but I'm not having it. She said to me, 'how would it be for you if you didn't have it anymore?' and I went 'look, I'm this person partly because of it, right'. It took me long enough to accept it, so other people have to accept it, right.

Similarly, when asked to whom she could talk about these issues, R3, who had also reconciled with her mother after a long period of estrangement, replied:

I dinnae go to my sisters or my mum because I feel that because I've got the virus, [...]and you learn life differently than what you would if you were just living normally no thinking about death, [...] and in that sense I feel that they're very naive..[...] I can ask my sister to look after my grandson or things like that, but as far as the HIV goes, [they're] nae good, .. I'm full-blown but they need the counselling you know.

Perhaps as a result of these difficulties, many respondents' pre-diagnosis friendships had died away. Some respondents explained this partly in terms of stopping work (R10, R4) or marriage or having a child as a teenager (R4, R12). Others, however, saw this development as associated with their diagnosis, or the related experience of bereavement (R12). R8 described starting to feel more comfortable with HIV-positive people than others:

I just started to see less and less of my friends from way back. [Is that because they knew... was it on their part that they started to see less and less of you?] Yes .. aye. But [...] I think a lot of that was me as well [...] back in '88, maybe '89, that's when I started to meet people with the virus and [...] I started to see more people that had the virus [...] as friends more than other people [You felt more comfortable with them?] Aye, aye...it's been a bit like that since really.

R9 was blunter:

[HIV] stops you forming relationships with people who are no positive.

R9 had several close HIV-positive friends, most of whom were gay men. Prior to her diagnosis she felt that she would have had little in common with them, whereas she now felt little in common with HIV-negative people. Such relationships may confirm Turner et al's recipe for successful caring relationships:

the helping literature suggests that caregiving should be less stressful for both caregiver and patient when they share similar attitudes and perspectives [1994, 1544].

While many respondents received practical support, therefore, from HIV-negative family members and friends, with some exceptions, informational and emotional support were less forthcoming. Emotional support seemed more easily obtained

from other HIV-positive people. The development of relationships with other HIV-positive people also reflected shifts in the respondents' post-diagnosis identities towards a greater acceptance of HIV infection, and, for some respondents, greater use of social space agencies, where they could meet other HIV-positive people. For some respondents, however, such support was available from within their extended families.

The Importance of Support from HIV-Positive Family Members

The existence of family information and support networks emerged unexpectedly from questions designed to elicit the chronology of respondents' service use. On reflection, their existence related to the association between HIV infection and injection drug use in Edinburgh, which left some families, including those of R2, R4, R7 and R8, multiply affected.

As with HIV-negative family support, however, there was no guarantee that such networks always exist or prove mutually supportive. This section will first concentrate on the numerous examples in the transcripts of the lack of support from HIV-positive family members and friends, particularly partners. Not all family members were open about their diagnoses, precluding their involvement in any such network. R8, for example, had been unable to talk to an HIV-positive brother who had later died. R4 suspected that a sister, who had also injected drugs and whose partner had died from AIDS, was also HIV-positive, but they had never discussed it.

Further, as pointed out in the literature on social support [Rook: 1992, 157], social relationships are not uniformly beneficial. R4's contact with her sister mentioned above had done her little good:

she just turned on me battering me and saying [...] that I think I'm fucking smart because I've got the virus [...] and I look the way I do [...] She hadn't been in my life since years and of course when she needed somebody, she came to me, so it's [...] really dragged me down a wee bit over the last few months.

Most strikingly, HIV-positive partners, potentially an important source of practical and emotional support, were mostly absent from the respondents' accounts of their informal carers. Interestingly, the respondents did not seem to expect partners to provide such support, or for their intimate relationships to reflect the values of trust and reciprocity, associated by Ungerson and themselves with informal caring relationships.

R10 recalled the lack of emotional and informational support from her late husband. Asked whether he had encouraged her to use services, she laughed:

No he just never spoke about me having it. I think it was guilt [at having infected her]...[He didn't get information for you?] No I think he just shut that out [...][Did you find that hard?] I think I just kindae accepted it [...]. Now I feel differently, I wish I had of talked about it ...strange.

Several respondents related abusive behaviour, and their accounts recalled my legal experience taking statements from women seeking non-molestation orders against violent partners. R6's former partner was involved in various HIV organisations, but would not permit her to use them for herself, leaving her extremely isolated:

he told them all I was negative [...]he was a very obsessive, possessive man, and I wasn't allowed to tell anybody because it would breach his confidentiality. So for four years I was surrounded in like a cocoon of unreality [...]too terrified to actually tell somebody, [...]I was alone, [...] I was already involved with positive people....[...] But it was really hard after sort of four years....of seeing these people everyday [...] and it ended up they had to guess [I was HIV-positive][...] I felt so bad about it...I mean I just fooled them [...]I suppose that I was controlled by him you know [...] I thought I was going off my head [...] I had noone..plus I think I was so emotional at times, I never verbalised it. It was just like pure bubbles coming out

R2 had also not been allowed to contact services for herself while caring for her HIV-positive husband. Re-reading the transcripts, I realised that R2, R3, R4 and R11 had all made oblique mention of previous violent relationships. The problem of 'gatekeeping' by male partners who controlled their female partner's service use was also emphasised by a worker at an information service for women, and a GP I

interviewed, who often encountered male hostility to their female partners consulting him.

These accounts indicate that HIV-positive relatives could not be relied on to provide any sort of informal support. Where respondents did have access to helpful family networks, however, they were greatly appreciated for providing information and advice from trusted sources. Asked whether she had obtained information through a brother who had since died from AIDS, R2 explained:

My brother was good at it because he was very direct [...] and made people tell him the truth. When he found out I was on AZT for example, he put them all down the toilet, ken because he knew that they were shite, and they were killing people off.

The extent of this family information and support network became clearer when I asked whether accessing information through this brother had affected R2's use of HIV-specific services:

Probably because we had that many affected in the family. One would contact one, and one would contact the other, and feedback to each other. [...] I was more the [drugs organisation] and [...] C [sister-in-law], [...] that died before, [...] she was more like CAST, SAM, she was in like battered wives' accommodation, and she was involved with all of they different services you've mentioned [...] cos of the time she had...but my brother just used certain ones, and I just stuck to the [local drugs] ones.

R4 provided another example of a family network in her second interview, again in response to my questions aimed at establishing a chronology of life events around service use:

[S: Do you think your brother-in-law's death made you want to use some services?] Well I don't know if consciously it did or not, but I have been in touch with [hospice] since then [and] [...] [another organisation] [...] See he was a great support to me, [...] I could pick up the phone and he was there...[....] constantly. Instead of me going out and getting services, he went out and got services in Glasgow, and he was passing the information on to me. So I think when he died, I

really missed him..even now I miss him. Because whatever it was I needed I could get off of him. So I suppose, since he died, I have had to get information off the other places.

R7's experience differed in that she and her brother did not discuss their diagnoses. However, she had learnt indirectly about the effects of HIV infection, and about some services, through him:

In the last year he was in [hospice] and when he was [there] I was usually staying there with him ..so [...] I learnt a lot through him, but no through him telling me ..[...] just through watching things like the changes in him, as time's gone on, and his health and his moods.

R7 also enjoyed support from HIV-positive friends she had known since before her diagnosis. It was very important to her to have retained this small group of friends associated with her multiply-affected home area, who could empathise with her. For example, the brother of her closest friend had died from AIDS, while this friend had herself had problems with alcohol. This group was particularly important when, as at the time of her second interview, R7 felt too tired and depressed to actually use services. She also appreciated being able to advise other group members about service use.

Several respondents had therefore gained information about their condition, available medication, and the provision of services through existing relationships with HIV-positive relatives and friends. These networks allowed them to forego using services themselves, without becoming isolated, as well as to protect their own, and their children's, confidentiality. To some degree, these networks further reflect the importance to the respondents' post-diagnosis identity of the potential for reciprocity. Similarly, the 'normality' of receiving help from people with whom they had a shared history, and of being able to 'keep it in the family' are also significant. In the next sections, however, I will examine the effects on the respondents' identities of not being able to rely on these networks long-term, and the generation, by some, of new relationships with other HIV-positive people, often through service use.

The Importance of New Informal Supportive Relationships

The Long-Term Impossibility of Relying on Family Networks

Although the respondents' family networks had often provided respondents with information and emotional support, during periods when little other help was available to them, the transcripts also suggested difficulties with relying on such networks long-term.

First, the reciprocity which was a feature of R7's group of friends was less evident in some family networks, where information-gathering was often undertaken by male relatives. The respondents themselves did not always see this as a problem. Such gate-keeping, however, raises several issues, including the gender-appropriateness of the information obtained.

Further, the multiple bereavements associated with these networks undermined them over time. This was playing on R7's mind in her second interview:

one of my friends just died and I was just at her funeral last Monday ... [...] another good pal [..]. I miss her and all.... That's another thing about this virus, [...] everybody seems to go. There's actually only 3 of us left..out the crowd. There was [...] 23 of us [..]who was brought up together, who had got into drugs in [..] our area, and there's three of us left... a couple of them committed suicide but the majority of them died with AIDS.

She also felt guilty about her brother's death:

K smoked heroin and he didn't inject [...] every day cos he was feared of needles [...] and I injected every day, and he came off drugs like 10 years ago. I only came off seven [..]no five, well seven, sorry. And [...] he was the first one to die [...] I had a lot of guilt about that [...] because [..]out of the two of us, I was probably the worst with drugs [...] I really felt that it should have been me [...] I miss him, I really miss him.

In spite of the risks associated with these networks, it was clear that the emotional and informational support they provided, underpinned by the values identified by Ungerson, was highly significant to these respondents. R2 and R4 considered that

the loss of these supports had made them more likely to approach social space agencies to meet other HIV-positive people. For some respondents, these agencies were the most obvious means of making contacts with HIV-positive people, and this became more possible after the respondents had re-negotiated their post-diagnosis identity to the extent that approaching these services became easier. In the next section, the importance to the respondents' identities of developing such supports will be examined further.

Generating New Relationships Based on the Same Values as Informal Care

The importance to the respondents of relationships with other HIV-positive people was clear. In fact, four respondents only mentioned HIV-positive friends on their lists of important people. The importance placed by the respondents on being able to make new contacts with other HIV-positive people was also signalled by answering my second interview questions as to preferred 'styles' of service use. Social space or 'meeting place' services were rated the most important type of service by 4/8 respondents. Only R1 and R4 did not use these agencies.

Like the family networks above, these new relationships were valued in terms of access to information, a point also made by Damen et al., with respect to self-help groups [2000, 333-4]:

You find things out. Every time, you learn something every day and you educate yourself about the groups and find out about things'(R12).

As R7 put it:

somebody'll talk about whether it's SOLAS, Milestone or Barnardo's. [...] it took me a long time to find out about all these things [...] SAFE, SAM, CAST, I mean I've not used them but it's all just from listening to people who have used them and that's how you find out about the majority of things really.

Her comments suggest that she preferred this means of learning about other organisations, from trusted contacts with the same condition, to reading leaflets or contacting agencies 'cold'. The preference for information from peers, based on experience instead of knowledge, has been emphasised in the literature on

empowerment, as discussed. However, it was also clear that these relationships were important to the respondents for reasons similar to those identified in discussions of the values underpinning existing informal supports.

For example, the respondents' explanations of the importance of these supports emphasised the values identified by Ungerson. Given that these relationships were formed post-diagnosis, long-term 'shared biography' was usually less important than with pre-existing informal supports. It was not entirely irrelevant, however. For example, R10 greatly appreciated her friendship with R11, precisely because of R11's links to her past:

it's all been in the last [...] 3 years since my husband died, because [R11] actually knew my husband better than myself. [...] [through] voluntary work [...] When my husband was in [hospice] I used to see [her] in there when she was a resident, and it just sortae came from there eh. We're actually going out every week now (laughs). [And has that been a help?] A-ha a-ha, [she]'s just right down to earth and I've asked her a few things whatever about HIV and things.

Her previous contact with R11, therefore, seemed to make their current relationship more 'normal'.

The following quotation, with its emphasis on sharing, also highlights the importance of the potential for reciprocity in these new relationships, another value associated by Ungerson with informal support through existing family and friendship ties:

you really need that [...] to share this with other people how you feel and realise that there are other women or men who are feeling the exact same way as you, you're not alone. And if you come to Body Positive or Solas, you'll meet people like that and you'll feel better about yourself (R3).

Several respondents' relationships with other service users had developed into close friendships, providing high levels of reciprocal support inside and outside the agencies where they had met. As R6, who had few sources of support, emphasised:

R3's really important to me [...] I've gained a lot from her.

She highlighted R3's emotional and informational support, while her response to my questions as to her activities over the previous two days indicated that she gave R3's daughter considerable practical support. R6 was also on R3's list of important people. By her second interview, her heavy volunteering commitments meant they saw each other less often, but they remained in regular telephone contact.

In her second interview, R2 insisted on adding R3 to her list of important people. R3 had advised her in relation to her concerns at her daughter reaching 16, and the similar combination therapies they were prescribed:

I [...] had these feelings, didn't know what they were about, phoned [R3]. [R3]'s been on a lot of the drugs that I've been on and she can like tell me about the side effects and ehm [R3] was just reassuring me like if I needed to go up during the night, because I didn't have the car, not to panic, just to phone her, she would come up and take me to the City.

R2 specifically appreciated the reciprocity involved in her friendship with R3 and her service use, commenting:

it's just [...] like say a family. That's the best way of describing it.

R9 enjoyed a similarly close relationship with a group of HIV-positive friends she had met through service use. Her use of the term 'family' to describe this group also expressed the reciprocity on which this relationship was based, and the concern to build a shared biography with these new supports:

I think what happens is you stick to your friends.... you have your own close circle of friends who become your family and you help each other.

For several respondents, therefore, the development of new relationships with other HIV-positive people was very important. The development of such supports was often dependent on the re-negotiation of identities with respect to HIV infection, to the extent that the use of social space agencies was possible. Once this was the case, however, the development of such relationships contributed to the 'normalisation' of living with HIV infection through involvement with others in a similar situation, creating a shared biography. These relationships also allowed the respondents to

participate in relationships to which their contribution, based on their knowledge of living with HIV infection, was crucial. It is important to recognise, however, that the development of such relationships is not without its risks, as will be discussed in the following section.

The Disadvantages of 'New' Informal Supports Created Through the Use of Agencies

Several respondents reflected on the risks of choosing to get close to other people with a potentially terminal diagnosis, emphasising that the emotional investment in these relationships, and the consequent degree of reciprocity required, could prove extremely demanding.

R10 recounted an experience of feeling drained by worries about the health of a close friend. This episode had led her to withdraw a little from another HIV-positive friend who was also going through a very difficult period:

I'm not as pally with her now if you like [...] she's got a lot of problems of her own and she's needing to sort it out just.... It's not such a good idea.

R9 mentioned numerous occasions on which she and her partner had helped HIV-positive friends and acquaintances. Consequently, she had witnessed many distressing incidents, and felt these activities had sapped her own emotional resources.

Such distress was magnified where newly created close friends died. R11's response to a general question, as to what she found difficult, was vehement:

my friends dying off on me. It calmed down in the last year. A year and a half before....my best support, my peer support....When I first started using services, of our support group [...], there are three out of 13 of us left. New people come along but it's difficult to get close to them. It's such a difficult one.. funeral and funeral and I wasn't well. I don't want to get close to new people ..if they die before me [...]. When I wasnae well [my friend] was sick.....with worry. [...] I just kept talking it over with my worker at the time from [...] A part of me wanted to fucking throw in the towel as well.

In general, the sections above have illustrated the importance to most respondents of connections of varying degrees of intensity, from close friendship to acquaintance, with other HIV-positive people. These relationships helped to reinforce the respondents' identities as people living normally as independent people, able to contribute to their relationships with others, in spite of their diagnoses. Some respondents also discussed the flipside of forming these new relationships, however, and, in particular, of exposing themselves to further bereavement. The remainder of the chapter will discuss the theoretical and other practical implications for service providers and planners of the importance to the respondents' identities of the values underpinning informal care.

Respondents' Conception of Informal Supports: Theoretical and Practical Implications

In the next few sections, the theoretical significance of this examination of different sources of assistance from the perspective of service users will be examined, followed by a discussion of the implications of these issues for service providers. Finally, I will examine the importance to the respondents' relationships with workers and professionals of the issues discussed in the first part of this chapter.

As discussed, theoretical examinations of informal support tend to assume that the relationships from which this support is derived exist prior to the cared for person's illness. The previous sections have suggested, however, that informal care should *not* be conceptualised only in terms of 'existing relationships'. Many of the respondents had developed relationships with other HIV-positive people subsequent to their diagnosis. These relationships were also based on the values identified by Ungerson as underpinning informal care.

Further, an examination of their accounts of the generation of informal ties suggests that the prevalent typology of services, focused on differentiating between service sectors, does not reflect the respondents' experience of the inter-relationship between the informal and voluntary sectors, in particular. Deakin, for example, focuses on structure and funding to distinguish between the voluntary sector (services with a formal constitution but run by unpaid management committees) and the informal

sector (a 'world of spontaneous of unstructured action') [1998, 162]. In contrast, the respondents' accounts did not distinguish between these sectors with respect to the generation of new informal supportive relationships, and the interviews provided numerous examples of different ways in which the supposed 'boundary' between these sectors could be permeated.

Some respondents preferred to meet friends only at social spaces agencies. Others had preferred to develop these friendships further in private, leading them to use the agency itself less frequently. This was particularly important to respondents such as R6 and R10, who felt shy and uneasy when using services.

Moreover, some connections formed through, but maintained outwith, service use had led to the establishment of parallel 'informal services'. Asked whether she belonged to an unofficial group, a standard first interview question, R11 replied:

Well I'd say Wednesday. Although we gather at [agency] ehm, it's an informal get-together group and we carry it on to the pub usually.

R11 now viewed this group, primarily composed of gay men, as an entity distinct from the social space agency at which they had met. This group was likely to affect her future use of services, particularly a hospice, as:

two guys [...]they're actually moving [...]and [...]they're suggesting that I stop using [hospice] or as much, and maybe go [to theirs] for respite. There wouldn't be any medical backup [...] but it will be peaceful and relaxing and guaranteed a nice time [...] It'll be great.

The connections made by R9, R2 and R3 through service use had led to the creation of new, more formalised self-help groups. As previously discussed, R9's friendship network had also developed into a self-help agency providing transportation and information to HIV-positive people in her home area.

Practical Implications of These Findings for Social Space Agencies

The Need to Take Account of The Existence of Informal Supports Inside and Outwith Agencies

The inter-relationship, even inter-changeability, between the respondents' use of informal ties and social space agencies in the generation of new informal supportive relationships also has practical implications.

First, these findings suggest that service providers should take account of service users' potential connections with other people, with the same condition, outwith the agency. Against this, it could be argued that word-of-mouth may be responsible for spreading inaccurate information, a concern relevant to the family information networks, analysed above. This, in addition to a lack of resources, may explain why, in spite of their awareness of the potential isolation of many HIV-positive people, the service providers I interviewed did not have any policies to encourage recommendations by word-of-mouth.

The potential for 'gate-keeping' within such networks, for example family networks, suggests, however, that service providers should not only be aware of such potential connections, but be prepared to discuss them directly with service users, and to provide differentiated information relevant not just to the client, but to others whom they might know.

Further, the respondents' attachment to gaining information and support through people they could trust, and whom they could help themselves, also reinforces the need to take account of such networks and relationships. R8 and R11's accounts provided a striking example of the effectiveness of word-of-mouth in encouraging service use. These two respondents had met through a non-HIV-related community group, become friends, and eventually told each other of their diagnoses. At the time, only R8 was in contact with a support group for people with HIV, as a result of a psychologist's advice. Before meeting R8, R11 had told no-one except her family of her diagnosis, made eighteen months previously. As such, R8's support was crucial:

She saw me through a lot of rough times [...] two's better than one [...] and she would encourage me to go and speak to the doctor or whatever.

R8 had also advised her to return to the City Hospital, reassuring her that the atmosphere there had changed, recommended a dentist prepared to treat people with HIV, and eased her use of an HIV support group:

I didn't know about any groups or anything to begin with but ehm [...] when I met [R8] and [...] she went to this group and I started going [...] and it just all stemmed from that and I started going to the local HIV and AIDS forum, about how the community were handling issues to do with HIV and AIDS, and I learnt a lot through that.

In fact, both women reported a very similar and fairly dense pattern of service use, very different to the service use of other respondents diagnosed at a similar time. The only major divergence in their service use related to children's services, perhaps because R8's children were older.

Issues Important to the Creation of Successful Social Spaces

The first two sections below will examine the implications for social space agencies of the importance of being able to build up relationships with other HIV-positive people to many respondents' post-diagnosis identities. The third section will focus more specifically on considerations relating to the structure of social space agencies, and the risks and benefits of cultivating intense informal supports among other HIV-positive people.

Crossing the Threshold – 'I'm not comfortable with just going in [...] and opening my heart'

Several respondents recounted the difficulties they had encountered when starting to use social space agencies.

As mentioned, social space agencies were not important to R4. In her first interview, however, encouraged by a chance meeting with two other HIV-positive women in a local pub, she suggested that she might try one such agency:

it's quite a cliquey place you know (a-ha) [...] if you don't walk in wi the right person they don't speak to you...[well] that's just my impression [...] never really a place I could go on my own... you know because although I can talk, I like to know

who I'm going with..[...]I mean with the two girls I'm going with it might be totally different.

By her second interview, however, she had still not been to the agency, indicating how difficult she found it to overcome her shyness.

Other respondents had become users of such agencies, but their experiences suggested that social space agencies should consider taking measures to help users through such initial difficulties. R7's first experience of one agency had put her off using it for years:

I didn't like it then, [...] horrible, it was actually quite a frightening place. [...] My health visitor, introduced me to the staff [...] in the café and she left, and she didnae come back for three hours, and in the whole three hours naebody spoke to me.

She hoped that her experience would not be replicated in the future, since workers now watched out for new faces, but was concerned that all agencies should consider responding to this problem.

R12 recalled her apprehension at approaching another agency:

It was harder to come here than it was to go to the social worker. [Why is that?] Because you're meeting people your own age [...] when you come [here] there's loads of people who are HIV-positive but you don't talk to them at first, and it's embarrassing and you have to introduce yourself.

A related concern for potential service users, whose self-esteem is low, is that the use of meeting place agencies might entail the possibility of rejection. Similarly, Fisk identified the fear of having to reciprocate as a factor in deterring some women with little confidence from using a community health project [1998, 160].

In the absence of pre-existing connections with other users of a particular service, workers and befrienders might play an important role in helping new users feel comfortable. This may be because worker-client relationships are moulded to a greater extent by pre-defined expectations. Several respondents in this study,

including R2 and R12, indicated that they would not have ‘got over the threshold’ without such help.

The Need to Be Aware of Potential Tensions Among Service Users

The transcripts also pointed to the difficulty of making all potential service users comfortable in the same space.

Certain problems of involvement in meeting place agencies were common to all, including internal politics:

It helped me at one point you know [...] for the first few months, but [...] You go in there sometimes to relieve stress, but once you start getting involved in [...] it's hard to say but people are very cliquey and [...] you hear a lot about politics and all that sort of stuff and it can become a place where it's not stress-free at all (R6).

Fisk also points to problems of possessiveness, where certain service users have been involved with the agency for longer and made a greater personal investment into it:

an unexpected problem [...] was that the women who were involved early on in the project became very possessive of the house, and this tended to deter the other women from using it [1998, 160].

Roy and Cain situate this problem in terms of the very diverse groups of people affected by HIV infection, a problem which was evident in Edinburgh [2001, 427]. Several respondents, who were former injection drug users, were adamant that they should not have to share facilities with current drug users. They criticised a residential facility vehemently in this regard, highlighting their general concern at being in proximity to drug use, but also, perhaps, a desire to distance themselves from that element of their former lives. One of these respondents also spoke at length, and with extreme bitterness, of a sex offender having been present at this facility during her last stay. Given this respondent's deep anger throughout her interview, as well as the widespread willingness to label people sex offenders, I chose not to investigate this matter further.

The Edinburgh respondents had the choice of two social space agencies, one of which was run on a self-help basis, while the other employed several workers. Several respondents, both users and non-users of the latter, criticised it as geared more to gay men than women. R3 made this point most bluntly:

[y] is very gay-oriented whereas [x] is mainly ex-drug addict, heterosexual women who've got it through sex and a few gays.

Four other respondents made similar points. These comments may reflect the observation of several writers that services developed by and for gay men are not necessarily appropriate for other groups [Feldman and Crowley: 1997, 122]. One respondent recognised that homophobia was an issue for some women, but emphasised that these feelings should not be dismissed.

Based on my limited observation of both organisations, I would suggest that some users of the self-help agency might feel excluded from the other 'gay-oriented' organisation on a class or education basis. This was suggested, for example, by the different language used by the workers, and by the interior decoration of each agency. Roy and Cain raise this issue with respect to the involvement of HIV-positive people as workers:

Organizations need to somehow help people of a wide variety of backgrounds feel comfortable, valued and respected, even if they come in without professional, middle class skills and experiences [2001, 430].

The attitude of the users of the self-help agency may also have been affected by a certain resentment at the greater level of funding received by the more middle-class agency.

The Need to Consider the Relationship Between Agency Structure and the Degree of Intimacy Engendered

As has been discussed, certain of the respondents' informal support relationships had blossomed into close friendships, providing high degrees of support. Equally, however, such relationships could place a great deal of emotional pressure on those involved, and some respondents were concerned to avoid the high degree of

reciprocity they involved. These findings pointed to the need to examine the relationship between the diverse structures of the services provided and the intensity of the relationships engendered within them.

At one end of the spectrum was the practical help agency analysed in the previous chapter. The figures its Manager presented indicated it was the most well-used service among HIV-positive women in Edinburgh, including among stigmatised groups such as current drug users. Although R11 had become very good friends with a volunteer from this agency, the general structure of its services demanded no reciprocity between users for the reasons identified by Fisk above.

At the other end of this spectrum, the entire structure of a self-help agency was dedicated to users meeting. Its rooms were open to all users, and there were no workers to facilitate interaction. This structure seemed to be associated with very high levels of involvement and reciprocity.

Two other social space agencies, one in Edinburgh and the other in Glasgow, provided social spaces independently accessible, or nearly so, from outside of the agency itself. One of these was a television lounge, the entry to which was close to main door. The other was a café directly accessible from the street. Workers also used these spaces but were not gatekeepers in any sense. The popularity of such spaces, not dominated by workers but within predominantly worker-led agencies, is also highlighted in the Positively Women survey [1994].

The respondents' comments of appreciation, particularly with respect to the café, highlighted the versatility of this structure. The café was popular both with respondents who preferred a high degree of involvement with other service users, as well as those who did not. The following comments also suggest how the readily understood, 'normal' structure of the café could be adapted to the user's needs or moods:

you have that safe space to meet people [...] [Do you feel comfortable in other organisations as well?] I do yeah [...] but I like this café, I like the relaxed atmosphere. Here you can speak away about what you like [...] and it's safe. Perfect. [What do you mean by safe?] Well you couldn't sit in an ordinary café

and it'd be HIV this or and they don't accept your sense of humour (laughs). [...] I just think the café makes a big difference.. [...]where you don't need to speak to anyone if you don't want to (R9).

it's got the café so it's more informal. [...] you can go to the café and you can actually talk to people. Whereas [another agency] I felt that I could be talking to someone at the front but that in the office they could hear everything what was getting said.... So I suppose that's probably why [this agency] is used an awful lot with the cafe... I mean you get folk coming in off the street that dinnae ken what it issome of them are quite horrified when they find out what it is (laughs) I love that! (R7).

These findings pointed to the potential advantages of spaces that allowed users to flit in and out easily, with fewer demands for reciprocity, and with fewer repercussions on fellow users, who might otherwise feel abandoned. For example, R9's comments above showed her appreciation of being able to go to the café, and not have to talk to anyone. She was able to use the café structure to control interaction with others without this behaviour being considered strange. She also appreciated being able to use these services according to how she felt:

I go through stages when I don't want to have anything to do with any of the services [...] I'm fine the way I am on my own [...] but at other times I feel I need to go.

At the time of the second interview, R7 was no longer using the agency she preferred regularly as she felt tired and depressed. She was, however, intending to use the agency to try and lift herself out of her depression:

I'm just sitting in that house which isnae really helping me so I feel like when I'm out,.. I haven't got time to think [...] I just have to get back into a routine [...] my sleep pattern's all went and ehm but hopefully I'll stick to it.

Workers also provided a means of using an agency less intensively. For example, some respondents preferred to offload their troubles on workers, rather than burdening fellow users, and potentially incurring a demand for reciprocity:

if I'm stressed out because I've had an illness and right away you think this is it back in, the virus and my count's gonnae be lower and everything else and you come in here and you tell one of the staff, and that, and they always seems to have an answer I feel. And if they cannae answer it, they put you onto someone else.

In this regard, meeting spaces also used by workers, such as the café or the television lounge, provided a means of overcoming fears of approaching workers for help. R12 described a gradual development of sufficient confidence to approach the different workers, through using the communal room. At first she had considered asking workers for help as embarrassing, almost like begging, but had grown to be comfortable with it. R7 also recalled gradually feeling more comfortable in approaching workers at the agency she used, for more specialised types of advice such as welfare rights, therapies and advice and information services.

The structure of these agencies therefore allowed these respondents to approach these sources of advice at a time of their choosing, after having had time to size up the workers involved, and without the apprehension involved in contacting an entirely new agency.

The interviews therefore suggest the potential benefits to service providers of understanding the links between informal support and voluntary services from the perspective of potential and actual service users. My analysis also suggested the importance, when planning social spaces, of taking account, of the significance of the respondents' post-diagnosis identity of living normally, as an independent person, and helping others. The findings also underlined the importance of providing for a variety of social spaces in order to reflect the different extent to which the respondents wished to engage with others at different times.

The Importance of Values Underpinning Informal Supports to Relationships With Workers

It might be assumed that the values, identified by Ungerson and in this chapter, as underpinning informal supports have little relevance to an analysis of the respondents' relationships with professionals and other workers. In particular, the classical professional-client model would seem to exclude any idea of reciprocity.

On reflection, however, several of these values were highlighted by respondents as important to their often long-term relationships with workers. In fact, several respondents criticised workers who had not, in some sense, become friends.

Shared biography has been discussed as underpinning many supportive informal relationships. Unexpectedly, the transcripts revealed that shared biography could also be an important factor with respect to the respondents' relationships with workers.

Initially, for example, both R2 and R10 had preferred to use local non-HIV specific services where the workers were already known to them, rather than approaching HIV-specific services. Although she had never used drugs and would sneak in the back door, R10 felt comfortable at a community drugs agency used by her husband. R2 had used another local drugs agency as the worker there knew all her family and drank with her father. Characteristically, she described her use of this agency as 'from family to family'.

Shared biography was also relevant to some respondents' relationships with professionals. As with her friendships, R10 preferred professionals who had known her husband, and to whom she did not have to explain her personal history. Similarly R4, who had had the same GP for fifteen years, commented:

she's absolutely terrific...she really is and she was stoppingsurgery and going toShe says to me to get you another doctor or do you want to come wi me ...I said I'd rather come wi her because I can walk into her surgery and she knows whether I'm alright or no.

In my view, Petchey et al.'s observation of the preference for HIV-positive gay male users to continue using the GUM clinic, rather than developing a relationship with their GP, may also partly reflect this preference for shared biography, as well as a desire to stay within a familiar, normalised environment [2000].

The finding that reciprocity could be a burden or disincentive to service use for some women might suggest that, for many HIV-positive people, a high level of involvement is unimportant, or a frightening prospect. As such, like R1 and R4, they

might prefer services which do not provide meeting places. They might also prefer the classical model of impersonal professional-client relationships. There were few, if any, expressions of approval for the classical professional model among the respondents, however. R4's comments came closest to endorsing this classical model:

I believe in counselling because they're objective, whereas my own friends would all side with me [...] and that doesn't always help to solve a problem.

She saw professional services as a means of maintaining discussion of her anxieties separate from her private life, and of avoiding placing an additional burden on those close to her. These reasons for appreciating professional services were found to be important by Mayer and Timms [1970, 42] in their study of users' relationships with social workers. They also seemed close to R6's and R10's explanations of their preference for the 'counselling' type of service use.

R4's mention of 'objectivity' fits with the classical one-sided, impersonal understanding of the professional-client relationship analysed by Davies [1998]. In general, however, the respondents' more positive comments about their often long-term relationships with professionals did not reflect an appreciation of this model. Rather, the interviews suggested that even professional-client relationships could become close, and that, where such closeness existed, the professional was greatly appreciated.

As has been discussed, several respondents held strongly critical views of professionals, particularly doctors and social workers. These views were often based on past experience, and had influenced their current commitment to the values of empowerment. On this basis, R3, whose comments were examined in the previous chapter, insisted on excluding any professional from her list of important people.

Also important to several respondents, however, was a feeling that professionals cared about them personally to some degree [also see Beedham and Wilson-Barnett: 1995]. R11 described how she had initially refused to go to hospital because of workers' unfriendliness and their assumptions that she had contracted HIV through drug use. She had only returned when:

they just got a whole new approach [...] friendly, wanted to know you personally.

Even R3 recognised that she enjoyed the informality of junior doctors, although she criticised the consultants' disapproval of such an approach:

the young doctors are fine.. oh they're brilliant these two doctors we had at the City [...] I loved them because they would come into your room and [...]lie on the bed [...] and 'how are you?' [...]. And that's a good attitude to have...feel so relaxed you know.

For several respondents, an important element of these relationships was mutual trust, a point also emphasised by Mayer and Timms [1970, 101]. R7 indicated how important this was to her relationship with her GP. For example, she had consulted her GP out of concern at the number of pills prescribed to her at a residential respite facility:

I told my GP...ehm I really love her. [...]I've only had her for maybe a year and a half now and used to be [...]intimidated by her [...]because she's quite a big woman [...]as if she's just been brought out the army...[...] but she's really caring. [...] It was the best thing that ever happened to me, I think, like medical-wise was getting her. Ehm and I says to her 'well I'm not wanting to take all these tablets' [...] And she's like 'fine, dinnae take them' [...] She's really supportive. She, she believes in what I believe in... whatever I want she's like well we'll try that..whether it's gonnae be good or bad she's always wanting to try something.

In several cases, very close relationships had developed, often over some time. Consultants and social workers were described as friends or members of the family. R4 recounted how she had remained in contact with a former drugs counsellor for numerous years, and continued to call her when in crisis. R2 expressed '100% confidence' in her consultant and a ward sister at the City hospital. She felt that her consultant cared about her as a person, and this increased her faith in his professional knowledge, even at a time when there were problems with her pill regime. In sum, she now saw him as a friend:

I mean he was upset as well last Monday, as well as me, he actually sheds his tears with me cos he feels that friendly. [S: So just like friends?] Oh aye! We just

celebrated our anniversary not long ago! I seen him more than I see some of my pals to be honest, I see him every month, 12 months out of the year....

R7 also emphasised her excellent relationship with a children's worker who had taken on an intense role in her family, and who had overcome her previous reticence at the idea of having a social worker:

I kindaē look at her as my mum [...] and the bairns, I think they think that she's like their granny. And she's started like taking them out on a Monday [...]after school for a couple of hours [...].and I mean she's not getting paid for it [...]. Me and my partner have meetings with [her] and when [we] get into like arguments, [she] comes down and she's like the referee (laughs). [...] As I say [she] was a social worker [...] but I really feel like at ease with her [...] I've got something special for her.

R4 and R11 also had very strong relationships with community social workers. Again, in R11's case, this worker had overcome an ingrained distrust of social workers:

[she] doesn't act like a social worker, she's really good.

She trusted this woman sufficiently to phone her, along with two HIV-positive friends, when she was upset.

It is interesting to note that these relationships were referred to in slightly different terms. For example, the more medical relationships seemed to be described by both women in terms of friendship, whereas those with volunteers or children's workers were sometimes characterised more as family relationships. This may point to the women's different perceptions of social as opposed to medical help, and an attempt to defuse any prejudicial implications of receiving help in these areas of life. These comments may also reflect similar experiences to those of Hughes, a social worker herself, and mother of a severely disabled child. Her distinction between 'alongsiders' (workers actually involved in caring) and 'assessors' (decision-makers at one remove from the family) may provide an interesting perspective on the some of the respondents' comments above [1995, 304-5].

The ideals of objectivity and emotional distance, associated with the classical model of professionalism, were therefore downplayed in the respondents' accounts of the relationships with professionals and workers which they most appreciated. On the contrary, the most successful relationships with professionals tended to be based on values associated with friendship and other informal supports.

Conclusion

The transcripts revealed a strong preference for informal support. This was important to the respondents in practical terms, but also because of the values underpinning the often high levels of practical support they received from family and friends. In particular, the respondents appreciated the existence of a shared history with carers, and the normality associated with receiving help from people to whom they were already connected, and to whose lives they had, and could still, contribute. As discussed, reciprocity was an important element of these relationships.

The transcripts also provided examples of family relationships from which such values were absent, however. The respondents' accounts of their relationships with their partners, for example, tended to confirm Rook's findings [1992] that, in certain circumstances, informal relationships may not only be devoid of any element of care, but may actually be harmful.

One problem with relying exclusively on existing informal relationships was that HIV-negative family and friends could not offer the emotional and informational support most respondents desired. These deficiencies had influenced the respondents' post-diagnosis efforts to build new relationships with other HIV-positive people based on the same values. Analysing the ways in which these new relationships were formed, and the values on which they were based, led me to question my conception of the relationships between different sources of help or service sectors.

On starting my analysis, I adopted an approach reflective of the distinctions drawn in the literature between informal and 'formal' support from the voluntary and statutory sectors. With this in mind, one of my initial questions related to whether the

respondents' service use was related to the presence (as suggested by McCann & Wadsworth: 1992, 30) or absence of informal support (as I had assumed). Early analysis revealed no such simple association. Some respondents with many informal supports were also frequent users of services (R11), while others, including R2, were not. In several cases, as discussed, starting to use services seemed to correlate with a lack of emotional or informational support, from other HIV-positive people, or a breakdown in such support, where it had existed previously, for example in family networks. It remained the case, however, that some respondents (R1, R4) with very few informal supports, including one who had previously had HIV-positive family support, were infrequent users of services.

The transcripts further suggested that a focus on distinctions between informal and other sources of support did not reflect the respondents' own conceptions of the different sources of support available to them. Instead, the respondents' accounts indicated that, once they had started to use services, the distinctions or 'boundaries' between informal supports and service use were permeable, even non-existent. This conclusion was suggested by the difficulty of disentangling the respondents' use of social space agencies from their development of new HIV-positive informal supports. Further, there were several examples of these informal supports developing into parallel, semi-formalised support groups. As such, it seemed that, from the respondents' perspective, what was important were the ways in which these relationships enhanced or detracted from their identities as independent people, living normally in spite of their diagnosis.

This conclusion is also suggested by the fact that similar values of shared biography and reciprocity seemed to underpin new, as well as existing, informal supports. Similarly, the values underpinning the respondents' informal support relationships were also important to their relationships with voluntary and statutory sector workers. Specifically, the values of trust, warmth, and even shared biography, often seemed to be more significant to the maintenance of these relationships than professional distance. In this connection, it is important to emphasise that the chronic and long-term nature of the respondents' diagnosis necessitated long relationships with some workers. In this context, it seemed that the relationships

with professionals, most appreciated by the respondents, were perceived by them to be an extension of their informal supports.

These findings have several implications for service planners and providers, relating, for example, to the physical design of services and the materials used to advertise them. These will be developed further in the conclusion to this thesis. In the next chapter, another important aspect of the respondents' post-diagnosis reconstruction of identity over time is discussed, namely the importance of maintaining control.

Chapter 8: The Importance of Maintaining Control to the Respondents' Post-Diagnosis Reconstruction of Identity

In this chapter, a final element of the respondents' ongoing reconstruction of identity will be examined: namely, the importance of maintaining a relatively stable post-diagnosis identity, once acquired. This concern was highlighted by the respondents' efforts to retain, in spite of numerous sources of uncertainty, their sense of control over their physical and emotional health, medical treatment and material circumstances. In the literature, these issues tend to be separated out and discussed in practical terms. These issues were, however, inter-related in the respondents' eyes, and crucially important to the maintenance of a coherent identity as living normally in spite of HIV infection.

In the light of their infection with a chronic, unpredictable and potentially fatal condition, the respondents' emphasis on trying to maintain control over their physical and emotional health is unsurprising. To analyse the link between the respondent's health and their post-diagnosis identity, this chapter draws on literature on the relationship between health and identity, including Crawford [1994] who views good health as crucial to modern identity construction as a rational, responsible person. Other writers emphasise the importance, for those who are chronically ill, of adopting strategies to obtain some purchase over their condition, and of trying to continue as normal [Crossley: 1997, 1998; Pinder: 1998; Wilton: 1999; Ezzy: 2000; Bury: 2001, Pierret: 2001].

The respondents' sense of control was also associated with their medical treatment and material resources, and, as such, greatly influenced by their interactions with the medical profession, as well as the social security and housing bureaucracies. The literature on health and identity was helpful with respect to the first of these concerns. Of particular assistance to an understanding of the inter-relationships between these issues, however, were examinations of user involvement in services [Jack ed.: 1995; Lindow and Morris: 1995; Barnes and Walker: 1998; Morris: 1998]. These writers emphasise the importance for people, with any kind of disability, to

‘exercis[e] choice and control’ in their lives, in general, as well as with respect to their interactions with services including bureaucracies acting as gatekeepers to economic and material resources [Lindow and Morris: 1995, 6,16, 23]. ‘Control’ is therefore associated, in this literature, with ideas of a personal, and sometimes collective, battle for self-determination. This chapter will draw on this work, much of which was published after I started this study, in exploring the importance of all of these aspects to the maintenance of the respondents’ identities over the years since their diagnosis.

The Importance of Control: Accounts of Unpredictability and Vulnerability

‘I vividly saw the process [of living with HIV infection] as a struggle to keep it from breaking through – a wall of water behind a dyke’ [Monette: 1998, 31 in Benson: 1997, 152].

On the basis of her interviews with a group of patients with another chronic and potentially fatal condition, Parkinson’s disease, Pinder identified several sources of uncertainty and potential loss of control. These included the barely understood trajectories of the condition itself, as well as the difficulty of coping with regimes of medication and their side effects over time [1998, 114]. As Pinder puts it, living with a chronic, unpredictable, and potentially fatal illness, inevitably involves:

contend[ing] with multiple layers of uncertainty and unpredictability [1998, 114].

In this study, these sources of uncertainty were compounded by the potential fragility both of the respondents’ status as good mothers and of their material circumstances.

The respondents’ difficulties negotiating these layers of uncertainty, and the consequent importance to them of developing strategies to resist potential losses of control, were highlighted by the methods used in this study. In particular, the use of two interviews provided the opportunity of comparing the respondents’ sense of control over their health and other circumstances at different times. Sometimes the contrast was dramatic.

In her first interview, R7 appeared happy, healthy and confident:

I've had the virus now since 1981, 16 years now and ehm really now [...] my tests and that are better than what they were 10 years ago.

By her second interview, however, she had withdrawn from using a voluntary agency, and from her social life. She had lost a lot of weight, and felt tired, breathless and depressed:

they think I've got a touch of depression and it's quite a strange thing because I really feel that there's something on my shoulders that's heavy.

The contrast between R2's two interviews was particularly marked. In the first, she enthused about the combination therapy she had recently started:

it was like the hope that I'd built up for it [...]that made me feel changed [...]. That blackness and that depression instantly left me and I had like three months to build up my hope against going up and getting my first result, and then I get the first result. [...]Instead of crying tears of sorrow I cried tears of joy.

However, just before her second interview, she had received worrying news:

everything was going fine right up until my appointment [...]but] it looks like the triple combination they put me on, which has really been doing me fantastic up to now, isnae working. [...]My consultant] told me my viral load had went up [...]. He said [...] we'll [...] stop all drugs you're taking. [...] I'll have to [...]start you on a combination that has to be monitored inside the ward. [...] One minute I'm thinking it's all hunkydorey and the next minute he's just took the gut clean out of me. [...] So when I went back last Monday I said to him ehm 'what happens now?' And he says 'I'm really sorry but I really thought this was the one'. [...] So he said to me like 'the choices are very bleak now, I'm not very sure like what we can do'.

Her concerns were compounded by her daughter reaching the age of sixteen, and the review, and potential loss, of her main benefit entitlement:

All of a sudden, 16, bad result, doctor negativity, DLA review, it's like boom, boom, boom, boom.

Her words suggested that she felt these threats to her sense of control almost physically, and perceived that a loss of control in one of these areas would inevitably lead to loss of control in all of the others.

Threats to the Respondents' Sense of Control Over Their Health

In the next few sections, I will discuss the importance to the respondents' identities of their fear of losing control over their health, and of the strategies they employed to try to prevent this. It is important to note that these fears were reinforced for several respondents by their prior experience of the loss of control associated with serious illness (R3, R4, R5, R8, R11, R12). As Melvin describes:

illness often brings with it feelings of vulnerability and loss of control over daily routines for the person who is sick [1996, 224].

Three of the respondents described themselves as having AIDS, according to definitions current at the time of the interview. All of these women had survived bouts of pneumocystic pneumonia [PCP], and several gave examples of the losses and sense of dependence associated with serious illness.

On the day after her interview, R12 was to be discharged from hospital after four months as an inpatient with PCP. She described her typical day as feeling:

really unwell, really dizzy, unfit, unable to make myself a cup of tea.

She was still experiencing breathlessness, and was particularly distressed by her HIV-related memory loss. During the interview, she was upset by her frequent difficulty in remembering my questions, and recounted other examples of the problems this caused her:

it's frustrating, it's really bad... [...] I can't even remember what I did yesterday. Probably sat [...] in the hospital and then went home..I don't know. And I said to my sister the other week there ehm, give me £10 the now to go to the van, and I came back in, and I never gave her the change [...] She says 'check your pockets' and I [did] and found all this change [...] and this had only been about an hour.

Several respondents (R2, R4, R7) mentioned having suffered ‘breakdowns’, while others indicated that they had also experienced problems in their mental health. In some cases, these episodes related to their physical health or to losing a relative to AIDS (R1, R2, R4, R7, R8, R10 and R11), while others highlighted problems with social support (R1, R3, R4), or with children (R1, R3, R5).

These experiences of loss of control ensured a continuing, acute sense of:

[bodily] vulnerability and porosity [Benson: 1997, 154]

among the respondents. Trivial complaints engendered anxiety that something worse would develop:

If I start feeling ill or I’m getting a cold [...] is it gonnae turn into anything else, will I get over it or will it..... (R5)

Similarly, R10 was troubled by the recurrent pains she was experiencing in her wrists at the time of her second interview. These anxieties were reinforced by problems with treatment.

Threats to the Respondents’ Sense of Control Posed By Treatment Regimes

The uncertainty surrounding the use of available regimes of medication was another source of the fear of losing control and, consequently, identity. Pinder describes:

the additional uncertainties, unpredictabilities and intrusiveness posed by the administration of the drug regimen. Clinically a balance is being sought between minimizing the symptoms of the illness consistent with incurring the lowest possible incidence of side-effects. It is a balance which, as the illness progresses, needs constant renegotiation [1998, 119].

Many respondents mentioned the uncertainty created by changes in their medication and by the side effects of treatment regimes. Like R10, R11 was concerned by slight changes in her health, but primarily by the potential side effects of her medication. Before I asked any questions in her second interview, R4 spoke for ten minutes about current treatment difficulties with her medication, and her relief that her recent appetite loss had resulted from the interaction of prozac with her HRT therapy, rather

than the failure of her HIV medication. Before this diagnosis had been made, however, she had found it impossible to stop thinking about her brother-in-law's sudden AIDS-related death. As she put it:

you never really can tell when a hiccough in your medication's gonnae happen.
[...] They gie you all this hope and then they take it back again which can be quite upsetting.

Another source of uncertainty related to the constant evolution of medical knowledge about HIV infection. As discussed, some respondents had been diagnosed as having AIDS, according to previous definitions of that state, but were no longer considered to have it. The unpredictability of current medication regimes did little to convince some respondents that theirs was a chronic, rather than a terminal, diagnosis.

In the next section, I will discuss the respondents' efforts to resist these threats to their health, emphasising the important links between these strategies to maintain their sense of control and their post-diagnosis reconstruction of identity.

Literature on The Relationship Between Health and Identity

A substantial body of literature emphasises the relationship between maintaining health and identity, with respect to both the 'healthy' and those living with chronic illnesses. The strength of this link, for example in Bury's idea of 'biographical disruption' [1982, 1991], has been discussed in Chapter Four. Crawford emphasises how:

serious affliction [...] threatens individuals with the prospect of varying degrees of disorientation and loss of control [1994, 1355. Also see Benson: 1997, 126-7].

Similarly, he identifies the way in which damage to the immune system and loss of control are intrinsically linked to loss of identity:

without immunity the self is overrun by other. The fantasy is one of ultimate loss of control and loss of self [1994, 1358].

In Crawford's analysis, this loss of control poses a serious threat to the affected person's sense of identity as a responsible, morally worthy individual:

The concept of health is absolutely central to modern identity. This assertion is premised on another: that health and the body imagined through it [...] *are not only biological and practical, although they are meaningfully these, but are also metaphorically layered*, packed with connotations about what it means to be a good, respectable, and responsible person [1994, 1348, emphasis added, also see Bury: 2001].

Crawford's points are made primarily with respect to the identity construction of healthy, middle-class North Americans. Other writers have explored how the fear of loss of control is equally important to those living with chronic illnesses, however. For Taylor [1989], the possibility of asserting a sense of control in the face of illness is important, not only physically, but also to the construction of a personal theory of the meaning of a condition, and of the correct way of responding to it [Crossley: 1997, 1863].

Pinder's interviews with a group of patients with Parkinson's disease raise similar issues to those faced by the respondents in these study. She analyses the patients' use of everyday strategies to obtain some sense of control over their condition, their medication, and their relationships with medical professionals:

Although seemingly small and insignificant, such attempts indicate *the struggle to regain some purchase on the arbitrariness of the illness*. To a greater or lesser extent, similar tactics were engaged in by most subjects in the group [1998, 118 emphasis added].

The practical importance of such strategies is clear. However, she also highlights the association of such strategies with 'living a normal life':

The *struggle* appears to be one of carrying on *as normally as possible*, in an attempt, [...] to recapture some of the '*taken-for-grantedness*' enjoyed by others [1998, 122 emphasis added].

Her findings recall the links drawn by Crawford between living normally, maintaining control and being a good, responsible person:

the claim of health is simultaneously a declaration of identity: 'I am responsible and rational', 'I am *in control* of my body and my life [1994, 1356].

Bury also highlights the moral nature of what he calls 'contingent' narratives that emphasise strategies of coping with chronic illness and 'normalisation' [2001, 274]. In his review of the literature on the narratives employed by people with chronic illnesses, he points out that:

various reports in the research literature testify to the importance of the practical management of illness in patients' accounts. In eliciting patients' stories it is important to note the centrality of these everyday mundane dimensions of experience [...]. Aspects of normalisation, coping, and strategic management of chronic illness figure prominently in patients' 'contingent narratives' [2001, 271-2].

In his view, such narratives are often 'performative' in character [2001, 273], associated with self-presentation as a 'morally competent actor' [Pinder: 1995, 624, in 2001, 273].

One aspect of the moral purpose of these narratives is how they may also be expressed as criticisms of those who fail to maintain control [Bury: 2001, 277]. For example, healthy people may attempt to reassure themselves that they will avoid a particular illness by associating that illness with a loss of control, illustrated by their engagement in certain, self-indulgent behaviours, or their inability properly to manage risks [Crawford: 1994, 1355-6]. In Crawford's analysis, the primary example of this tactic of the stigmatisation of irresponsible 'others' is people with HIV infection:

AIDS, in its association with illicit drug use or an illicit, promiscuous, or extra-marital sexuality, powerfully reinforces this notion of health as the property of the normal self [1994, 1356, 1358].

Interestingly, Crossley's analysis of the comments of members of a self-help group composed primarily of educated, HIV-positive gay men, suggests that they employed similar strategies of projection to underline and protect their own health. Group members identified themselves as 'long-term survivors' and contrasted favourably

their emphasis on ‘positive thinking’ with ‘others’ whom they classified as ‘weak-minded’ [1997, 1869]:

the HIV-positive ‘survivor’ eventually comes to believe that it is this difference that accounts for his/her ‘survival’. When this happens [he/she] is forced to maintain a boundary between his/herself and the constructed ‘others’ as a means of preserving his/her identity as a ‘survivor’. It is in this regard that the ‘healthy self’ ‘unhealthy other’ opposition begins to serve as a ‘sentinel to patrol the boundaries of acceptable identity [1997, 1870].

Another element of the ‘moral’ purpose of these narratives, explored in the literature, is the importance attached to the decision-making power of the person affected. Crossley’s respondents emphasised the need for ‘empowerment’ with respect to medical decision-making in particular, characterising medical professionals as impediments to the exercise of this power [1997, 1870]. Benson [1997], Pinder [1998] and Bury [2001] explore the importance of battle imagery to people with chronic illnesses more generally. For Bury, this imagery of ‘fighting’ is representative of a heroic ‘core’ narrative [2001, 278]. For Benson, such imagery is associated with the importance to post-diagnosis identity of being able to make choices, of being able to take action on one’s own behalf, and of:

reclaim[ing] for their situation, what, through their infection they have lost: *agency and efficacy* in the context of their own embodiment [1997, 159 emphasis added].

In the following sections, I examine the importance of asserting control in relation to emotional and physical health to the respondents’ efforts to maintain their identities.

Respondents’ Reports of Their Attempts to Maintain Control Over Their Emotional Health

Several respondents emphasised the strategies they employed to prevent themselves from falling prey to anxieties resulting from the numerous uncertainties attached to living with HIV infection. Their accounts highlighted the self-discipline involved in employing the various strategies, analysed in the sections below.

The Importance of Living in the Present And Not Making Future Plans

The only long-term ambition stated by the respondents was to survive until their youngest child reached the age of sixteen [See Chapter 5]. With respect to their own, as opposed to their children's, futures, however, only two respondents (R7, R10) expressed fairly vague personal ambitions, specifically to travel. A third, R4, was cautiously optimistic, having been predicted ten years of future life by an astrologer.

In contrast, most respondents, including these three, strongly stated the importance of a mental resolution *not* to make concrete plans for their own future. Living from day to day was seen as a means of exerting control over the uncertainty of their situation or, as Charmaz puts it, of managing chronic illness [1991, 178 in Pierret: 2001, 171].

In the first interview, I asked each respondent, except for one who was very ill, how they saw their lives in two or three years' time. In response, 10/11 respondents stated that they did not think about the future. For example:

You cannae plan anything you know because ...I was like this one day and the following day I was lying with a 104 temperature...rushed to the hospital [...] just honestly like that. So [...] I live from day to day (R3).

I never plan no, and then you never step into a disappointment (R6).

Such comments may recall common self-help-style exhortations not to worry about the future, particularly in the context of a lack of financial resources. From the context of these remarks, however, it was clear that they were made in response to the unpredictability of living with HIV infection, and that the implementation of this strategy required constant vigilance. R4, for example, related an occasion when she had lapsed from this strategy, only to then suffer a problem with her medication:

After all I'd been through in the last year with my brother-in-law being ill, I thought I was just gonnae have this year [...] when I wouldnae have to worry about anything [...]. And the one time I done it, [...] things happened.

Other respondents emphasised the importance of avoiding negative thoughts as their primary reason for adopting this policy. R5 equated thoughts of the future with thoughts of her mortality:

we really don't talk about the future unless it's negative thoughts.

When asked about her hopes for the future by a volunteer, R7 also seemed to associate the future with thoughts of serious illness or death. Her account suggests a personal modification of the accepted formulation of this strategy among fellow users of the agency she attended. Fundamentally, however, her point remains the same:

I dinnae really see a future for me ehm, so I'll take every week, I didn't say every day because I dinnae look at it every day, but take it as it comes because one week I can be fine and the next I can be like seriously ill.

The transcripts therefore illustrated the respondents' concern to discipline their thoughts with respect to aspirations for the future. Making concrete plans for the future was regarded as dangerous. Some of Pierret's respondents, perhaps influenced by the interview context which provided them with an opportunity of reflecting on the past, suggested, in the light of their continued asymptomatic status, that this approach might have robbed them of various opportunities [2001, 171]. Perhaps because of the various illnesses suffered by several of the respondents in this study, none of them took this point of view. By attempting to counter thoughts of the multiple uncertainties associated with their condition, however, the respondents sought to 'normalise' their situation, to avoid losing control over their emotional health and to present themselves as fighting to retain control. A similar strategy is discussed in the following section.

The Importance of Not Letting HIV Infection Dominate and of Positive Thinking

Several respondents, including R10 and R1, emphasised the importance of not allowing their thoughts to be dominated by HIV infection and its potential implications. After being told she had AIDS, for example, R5 had decided to cut down on her contact with other HIV-positive people:

I used to have a lot of gay men friends but I dinnae see as much of them[...]maybe because things have changed for me and [...]Some of them are just too heavy, and they just go on and on [...] all they wannae talk about, [...]is HIV [...] I keep away from it cos [...] it depresses you.

Her comments pointed to a concern to reassert a sense of control over the space occupied by HIV infection in her thoughts.

Similarly, R4 had developed a personal image of control over HIV infection, an image which separated the virus from her body physically, and provided a means of maintaining this separation:

I'm mainly concentrating on what I've always done, I suppose, on the keeping well aspect and not dwelling on being HIV ...[...]whatever's happening health-wise.. I cope with it and then it goes *in the cupboard* and you get on with life.

She used the same image to explain how she and her daughter would discuss the results of each of her hospital appointments together, and then leave the subject alone. This was also the technique they had used to try to move on from grieving for a family member who had died from AIDS. R4's use of this image may have been the result of her experience of counselling. However, her particular formulation of this image would seem to be particularly vivid, suggesting her own personal investment in it.

Similarly, R5 emphasised the importance of what she called 'positive thinking':

Sometimes you think 'oh God, I've got AIDS, I'm gonnae die' and then I just think, 'oh God stop being ridiculous' [...], and you just have to sortae think of it like that.. because you get yourself into a rut.. and you will just get depressed and [...] it's [...] *mind over matter a lot of it* (R5).

These respondents emphasised the importance of strategies to control the place of HIV and its potential implications in their thoughts. As with R4's image of putting the virus 'in the cupboard', these strategies were aimed at avoiding loss of control by shoring up mental defences against HIV infection. They recalled Pinders's focus on:

the *struggle* to regain some *purchase* on the arbitrariness of the illness [1998, 118, emphasis added].

These strategies also illustrated the respondents' determination to establish and maintain their identities as people exercising a level of control over their situation.

Some respondents took these ideas further, adopting an identity as a 'survivor', a fighter. Like the respondents in Pierret's study, they:

attached the most importance to psychological qualities: 'to have high morale' was the most frequently used phrase for describing, even defining, themselves [2001, 166].

Their explanations for their continued survival also employed similar tactics of projection to those analysed by Crawford [1994] and Crossley [1997]. Like R2, R5 was critical of those HIV-positive people whom she saw as doing little but complain about their condition. R3, particularly, had harsh words for those whom she saw as 'moaners'. In her view, their inability to think positively, avoiding thoughts of the implications of their diagnosis, explained their premature deaths:

You have to try for things in your life, otherwise you'll never get them [...] just a shame that all the other people dinnae learn that ...they're all deid...they were so busy worrying about themselves dying.

Her comments recalled those made by members of the self-help group, interviewed by Crossley, who defined those who did not adopt a strategy of 'positive thinking' as 'weak-minded' or 'negative':

the kind of person who, when diagnosed positive becomes obsessed with the fact that s/he is going to die, sits there day-in-day-out thinking or talking about it, and in the manner of a self-fulfilling prophecy proceeds, inevitably, to die. Most survivors had a story of someone like this. These weak people are held responsible for their own deaths. They are seen as choosing to die [1997, 1869].

For the members of this group, and, similarly, for some of these respondents, the self-discipline involved in their adoption of a strategy of 'positive thinking'

distinguished them morally from those ‘others’ who died early, and protected them from this fate.

Respondents’ Accounts of Strategies to Maintain Control Over Physical Health

‘It’s great when you control and feel normal again’ [R10 with respect to another condition]

Several respondents were at pains to emphasise the measures they had taken to protect their mental health, and the self-discipline required for the consistent employment of these measures. With respect to their physical health, many of the strategies discussed related to the need to negotiate with the medical profession, and to obtain some ‘control’ over treatment decisions.

The first section, however, will address a health maintenance strategy aimed at preserving energy by cutting down on strenuous activities. It was interesting that, as discussed in Chapter Five, several respondents found it difficult to assert this positive choice without reservation, where it conflicted with activities they perceived as important to their roles as good mothers or housekeepers.

The Importance of Saying No

All of the respondents, including those classified as ‘asymptomatic’, emphasised the problem posed by chronic fatigue, and the need to work around it to preserve physical energy. Several respondents explained how they had adopted certain days of the week as rest days, planning their activities and appointments to fit into the remaining days. This strategy was often explained as acquiring the self-discipline to ‘say no’.

Several respondents, for example, recounted the difficulty involved in learning to be less house-proud:

I used to do the house every day, all the time, [...] I was a maniac about it [...] whereas being no well, I’ve learnt that the house will still be there the following day [...] I had to learn that when my body tells me to stop I have to stop. [...] That was hard to learn I must admit. It took me about three years to learn (R2).

Her strategy was to do as much housework as possible on days she feels well because she ‘could be ill the following day anyway’.

Social and family obligations were other areas in which the respondents found it difficult to ‘say no’. R5 spoke of having to learn to cancel social engagements when tired or ill. R10 emphasised:

I find it hard to say no. So I think I’m gonnae try and [..] start saying no. I’ve got a couple of friends that have got HIV themselves so I think why don’t I just see how I feel because it’s silly because they know anyway.

R4’s account also emphasised the difficulties she had experienced in adopting this strategy, and emphasised how a minister had legitimated her use of it:

I’m learning to take time out for myself...[....] switch my phone off and things like that. [...]I learnt to do that about five year ago because [...] I had elderly aunts that I used to do quite a lot for...even after I was diagnosed [..]. A few year ago when I had [...]three years when I was really unwell, and I was finding it harder and harder to cope with [helping them], the Minister [....]he helped me a lot in saying look, take time out, [..]for yourself....[..]so I learnt to do that and I do do it...[..]if I find things are coming in on me I just shut the world out and just have time for myself.

Similarly, she related how she had excluded from her life a sister who had been very emotionally dependent on her, and who had physically attacked her.

In certain, often gendered, contexts, therefore, emphasis on the importance of asserting control over their physical health was perceived to conflict with other responsibilities of equal or greater importance to their identity, such as being a good housekeeper, mother or family member. Most of the strategies discussed by the respondents with respect to protecting their physical health did, however, emphasise the importance of asserting control in less ambivalent terms. For example, most respondents highlighted the techniques they employed with respect to their interactions with medical professionals.

Control and Medical Treatment

All of the respondents attended, or had attended, hospitals specialised in the conventional medical treatment of HIV infection. For those few respondents who were asymptomatic, this involved twice yearly hospital trips for blood tests. For others, contact was often monthly, and their treatment often involved compliance with complex and onerous drug regimens.

Pinder [1998] and Crossley [1998] both discussed medication regimens, as well as contact with the medical profession itself, as major sources of uncertainty, over which chronically ill patients were likely to wish to assert control. This was also a major concern for some respondents in this study, although manifested in different ways. Few respondents shared the extreme scepticism of conventional medicine of many of Crossley's respondents. Nor had they developed the confidence of some of Pinder's respondents, who regulated their own levels of medication. In this study, compliance with rigorous regimens of medication was presented by several respondents as an expression of their determination to battle against HIV infection. At the same time, most respondents were also very concerned to exercise some degree of control over the medical decision-making process.

The Use of Orthodox Medication to Control Physical Health

Most respondents who were receiving medication indicated that it was very important to them. When asked to rank the importance of various types of service provision to them, R2, R4 and R12 said it was the most important aspect of their care:

I think the main aspect to my life is making sure that my medication's correct [....]
that has to come first (R4).

For her, treatment decisions took priority over other decisions:

Obviously I have to wait until April [..] to find out if I'm gonnae go on the medication or not. Once that's settled, whatever way it goes, then I can decide what am I gonnae do now..am I gonnae get out in the garden or go to [agency].

At the time of their interviews, several respondents were preoccupied by issues relating to combination therapies. Of the six respondents who were receiving these therapies, two were unreservedly enthusiastic. R8 credited her treatment with her renewed energy, after a period in which she thought her death was imminent. When asked what she would advise a newly diagnosed mother to do, R5's succinct response was 'combination therapy'.

The level of success attributed to combination therapies, at the time of the interviews, seemed to exert pressure on respondents whose condition might indicate their use, but who had not yet taken the decision to use them. R4, for example, discussed her difficulties deciding whether or not to start a combination therapy, at length, in both interviews. On the one hand, she preferred to take all her medication in one go each day:

from that to taking different tablets every four hours or whatever [...] it's quite a horrendous thought.

On the other, as a 'responsible person' in Crawford [1994]'s terms, she seemed to feel obliged to start a combination therapy.

Once respondents had decided to take combination therapies, the self-discipline involved in compliance underlined their unremitting battle against HIV infection. Many respondents emphasised the large number of pills they were obliged to take, at strictly defined times of the day. Others highlighted the nausea and other unpleasant side-effects associated with taking the pills.

R2 had had to persuade the hospital to put her on combination therapy when it was suggested that insufficient funds were available. She described compliance with the combination therapy regimen as a battle of self-control. She was suffering from intense feelings of anxiety, nausea and dizziness, night sweats, difficulty absorbing food, and rashes. In spite of these side-effects, she was getting up each day at 7.30am to take her first set of pills to be followed by two others, eight hours apart:

when you're taking a lot of tablets it's really difficult to stick to them [...]. (S: On my last interview I have about 10 minutes of you taking tablets) Oh, fuck. They

really get to you these, you just want to flush the lot, and then you think dinnae be silly ken, this is here to help you. *It's like a battle of wits game going on in your brain.*

R11 found it very difficult to swallow the pills she was prescribed. She was hoping that a drugs company would allow her to test a new version of the same pills, resulting in a reduction in the number and size of the pills she needed to take.

R12 was also weary of her drugs regime, but had agreed to try an experimental combination after developing a resistance to a previous prescription. Despite some fatalistic comments, the main tenor of her comments was a determination to fight to stay alive:

I hate it, but I've got to take it, I'm dying. I don't want to die, I want to see my daughter grown up, so it's hard but it's got to be done. And it's got to be done on time all the time, eight, two and 12.

For several respondents, therefore, their compliance with onerous regimes of medication was an example of their determination to obtain some 'purchase' over their condition [Pinder: 1998], and to act as 'responsible people' [Crawford: 1994].

A few respondents found it difficult to adopt this stance, however. R3's ambivalence towards combination therapies was quite marked. She was concerned that the number of pills she was taking each day would place too much pressure on her liver, already damaged by Hepatitis C. She presented her compliance with this regime of medication more as a limitation on her sense of control than an expression of it:

I woke up at 10 so I was three hours behind and I cannae take them because you end up with too much toxin in your body and [...] nauseous [...] there's nothing you can do, but then you become resistant to the drugs so you cannae win [...] because *my only other choice* is to come off.

R3's use of the word 'toxins' also recalled Crossley's respondents' questioning of medical expertise, and general antagonism towards orthodox medicine. The implications of this viewpoint will be further discussed in the following sections.

The Use of Alternative and Natural Therapies to Control Physical Health

Many respondents emphasised the importance of eating well, and of taking vitamin supplements. Alternative therapies, such as aromatherapy, raiki and massage, often provided by voluntary agencies, were also very popular. The respondents' attachment to these remedies recalled Pinder's observations of the struggle to 'regain some purchase' over the arbitrary progress of Parkinson's disease. One of the patients she interviewed said of his yoga classes:

it's a bit less lack of control really [1998, 118].

In most cases, these therapies were employed alongside the use of more orthodox medication. Some respondents, however, were more ambivalent about conventional medicine, espousing 'natural' remedies in terms reminiscent of the idea of 'empowerment' identified by Crossley [1997, 1998]:

a [more] common perspective among the group was one which was sceptical of the medical profession and associated medical technology and knowledge. Their scepticism centred on perceptions of the uncertainty, incompetence and lack of knowledge of the medical profession concerning HIV/AIDS [1998, 516].

Like some of Crossley's respondents [1997, 1870; 1998, 516], who emphasised their rejection of any treatment containing 'toxins', R9, perceived conventional medication as polluting her body:

I prefer to take vitamins and herbal tonics..... [Which kind?] Well I take echinacea which is for your immune system. I'll take vitamin C if I remember.....um..... I go to a homeopathic hospital as well [...] that's my way....*I like to be responsible for myself. I don't like toxins*..she says with a fag (laughs)! but I would rather do that first than this combi therapy [...] [Did you know about homeopathic remedies before your diagnosis?] Ehm..I'd been interested in them yes. But I'd always been interested in the natural things so it was an obvious choice for me.....

For R9, therefore, her use of natural remedies, and irregular attendance at hospital, was a means of emphasising that she had choices, and had remained true to herself in spite of her diagnosis. In other words, it allowed her to assert her own sense of

control instead of complying, passively, with medical strictures. While not ruling out the use of conventional medicine, R9's stance also questioned the exclusivity of medical knowledge, a theme which will be developed in the following section.

Trying to Maintain Control in Relationships With Medical Professionals

Overall, respondents reacted in varied and contradictory ways to medical professionals. The lasting effects of the prejudice, breaches of confidentiality and unprofessional practice, encountered by many respondents at the hands of medical staff, have already been discussed. More recently, many respondents had had more positive interactions with health professionals. R2, for example, was effusive in praising her consultant, whom she regarded as a friend. Even R9 said she would advise anyone with HIV to attend the City Hospital.

The concern to maintain a sense of control in their relationships with medical professionals was, however, a major preoccupation of most respondents. In particular, they were concerned that medical staff should provide them with adequate information, and respect their views in the decision-making process as to their treatment. Others went further, questioning the quality and exclusivity of medical knowledge.

The inequality inherent in the doctor-patient relationship was, in various guises, of concern to many respondents. This power imbalance has been the subject of much medico-legal literature over the last few decades [Katz: 1984, Gibson: 1995; Anderson: 1996], and of landmark legal decisions on the meaning of consent and informed consent with respect to medical treatment.¹

In the medical context, the legal requirements of consent and informed consent aim to protect the patient's autonomy or right to self-determination, in the face of this medical power:

¹ The case of *Re T* (1992) 4 All ER 649 (in England and Wales) held that patients may refuse treatment even where the reasons for a decision are irrational, unknown or non-existent.

informed consent reflects one of our highest societal values, individual autonomy. It reflects a strong emotional need for control over our own lives and an admission of our dependence on others, and it deals with a subject of fundamental importance, our health. (Lidz et al.: 1984, 10).

In spite of these legal protections, several writers on medico-legal issues consider that medical paternalism remains an important influence on the outcome of the medical decision-making process, and has been more prevalent with respect to women patients [Sheldon and Thomson: 1998, 26]. A case in point is that of Caroline Richmond, an articulate, middle-class woman, whose ovaries were removed, without her knowledge or consent, during a minor operation in 1992. Although critical of the hospital's consent procedures, the General Medical Council did not censure the doctor involved [Blackstock: 2000, 6].

These respondents' concerns that their decisions about treatment would not be respected were based on their own past experience, for example, of being tested for HIV infection without their consent. The Positively Women survey also found that 40 percent of its respondents, diagnosed before 1988, had not consented to a test, and that 40 percent, diagnosed since 1990, had received no pre-test counselling [1994, 5-6].

R2's, R3's, R5's, R7's and R10's trust of medical professionals had been further undermined by having been prescribed very powerful drugs without discussion of their side-effects. R3 recounted that she had been refused valium, a drug she trusted:

[So] I trusted her to gie me this pill [...]and I was out for two days..and I've never trusted [the agency since].

R2's similar comments related to having seen the effects of largactyl on her sister-in-law. R7 further recounted:

the last time I was at [agency]...they put me on these tablets for depression, and I was like a zombie.

R10, who had never used drugs, resented being prescribed a drug associated with problematic drug use:

after my husband died I was very agitated, I wasn't sleeping at all [...] and I got put on a course of temazepam and it really freaked me .. because I was totally against that sort of thing.

For several respondents, this fear of medical professionals' power was compounded by their experiences of coercion in treatment decisions. R11 was angry that a consultant had, in her words, blackmailed her into starting combination therapy by emphasising the effects on her children, should she not start treatment and die. R10 referred to another such incident of blackmail, although she refused to explain what had happened.

R2 also highlighted the potential for coercion with respect to substitute prescriptions, an issue also raised by Huby et al. [1995, 26-7]:

I was on AZT at one point and it wasn't suitable for me, and I told her I was thinking of not taking it, and her attitude was well if you're not going to take AZT we might have to think about cutting down on your diazepam.

Similarly, in response to the 'flashcards' I used in the first interview to elicit unguarded and emotional responses to various agencies, R3 described the City Hospital in the following terms:

I dinnae trust them ... want to control my life as far as the drugs go, has got strings attached, bit bossy, not open to my ideas.

Another source of doctors' influence, mentioned by respondents in Huby's study, as well as this one, was the power of GPs over material circumstances. Several respondents emphasised that letters from GPs in support of applications for benefits and housing points are crucial to their success. Huby et al. found:

the service user's dependence on the system of medical treatment for money and drugs introduces an element of fear of manipulation into the relationship between service provider and user [1995, 38].

R8, who had stopped using the City Hospital after a doctor had insisted on taking blood only from her groin, highlighted another source of potential manipulation.

Similarly, R3 was suspicious of a doctor who asked her to remove her clothes without a nurse being present.

Based on these, and similar, experiences, several respondents had taken measures to try to ensure that their choices would be respected should they became very ill. R5's explanation of her decision to make a living will related to instances of coercion she had witnessed in a residential facility:

when I get ill I'm not going into [hospice], I'm not going into [hospital], [...] I'll stay here (right yes)... 'cos I've seen how they treat people who are ill or senile [...] and they're not doing that to me.... [Have you made a living will?] I've got one... I've told my mum, [...] everybody that's close to me [...] [that] I dinnae want to be put into one of they places.

R4 had also signed a living will, prompted by the aggressive treatment of her late brother-in-law, condoned by his family. She wanted to be cared for at home, by her daughter.

Most respondents, therefore, were concerned by medical professionals' power to influence their consent to treatments. Informed consent was another important issue. Some respondents complained that doctors had not provided them with adequate information relating to these decisions, a concern also emphasised by Pinder:

[t]he need for patients to feel in some sort of control over what is going on, yet confronted with a profession apparently reluctant fully to share the information necessary, suggests that an inappropriate model for dealing with a chronic condition is being applied [1998, 119].

In their survey of attitudes to medical decision-making among people infected with HIV through injection drug use in Edinburgh, Carretero et al., [1998] also found that a high value was placed on patient participation: patients wanted more medical information than medical staff anticipated [323-8].

Some respondents in this study were, however, more cautious about their involvement in actual decision-making, an ambivalence also reflected in the Carretero study. R11, for example, thought that a friend's insistence on obtaining

every possible scrap of available information had led to her premature death. R4 was particularly concerned to limit the information she received about potential side effects of drugs in case she started to convince herself she was experiencing them out of anxiety. She also commented:

[e]arlier this year I had a problem with one of the medications I was taking and I had come off that.. so I find it hard sometimes because they don't say to you 'take this or that', they say to you well 'do you wannae try it'. [...] That is very hard because you have to decide yourself [...] which I agree with [...] because it's like my body [...] but I find it very difficult to cope [...] To me information is good if [...]limited [...] because too much information would just confuse me, and it would just stress me out, and I would never make a decision.

To reduce the potential for receiving contradictory and disconcerting information, R4 also made sure she saw the same consultant, refusing to see another who had once given her different advice:

I says I'm no being funny but I really dinnae have any confidence in her because she had contradicted everything that [usual consultant] had said to me.. but that's nae good to me because [he's] the boss.. so I mean she really took my confidence away.

A local GP I interviewed also observed that many of his patients liked to minimise uncertainty by obtaining information from one source.

Despite the additional responsibility involved, most respondents were concerned to assert some control over their relationship with medical staff. For many respondents, this concern had evolved gradually. For example, in a manner reminiscent of her acceptance of her husband's refusal to talk about his diagnosis, R10 described how, initially, she would not question medical decisions regarding her child. Recently, she had started to do so, and had developed a strategy whereby she would take people with her to medical appointments to back up her opinion, retain the information given, and help her consider it further.

R2's blunt requirement of her consultant was that he tell her the truth:

he tried to be a doctor, doctor and I just said to him ‘listen, I need to be cards on the table. Every time you see me nae lies, blunt as you like, hard as it’s coming’ [...] and since then, fantastic.

Several respondents therefore focused on ensuring a greater level of involvement in decision-making. Some respondents’ re-evaluation of their relationship with medical professionals went further than this, however, to question the locus of expertise in the professional-client relationship and to assert a much greater level of responsibility for and control over their treatment. Despite their continued, if sporadic, use of medical services, these respondents were prepared to question one potential premise of the professional-client relationship, identified by Turner:

[t]he specialisation of knowledge and the delivery of a service on the basis of skill and expertise are accompanied by the absence of specialised consumption by the client [1995, 133].

R9’s preference for alternative remedies has been noted. R5 and R3, in particular, emphasised that they were not overawed by their consultants’ expertise, and would question consultants’ claims to knowledge, if necessary, with information obtained from the internet:

[when diagnosed] I believed everything my doctor says. It took me having HIV to disbelieve them [...]. Because I’ve seen my doctor give me information and say ‘ah ah, I read that on the computer last night and that’s rubbish’. [...] You know I talk to my doctors like that, [...] they’re just men. I mean we’re all open to mistakes, and I don’t think being a doctor makes you any different ken from anyone else (R3).

In her second interview, R3 was furious and upset with her consultant for not informing her of all the effects of her combination therapy on her body, including her fertility. In the same vein:

I’ve had the same consultant for eight years [...] [last month] [...] he was sounding really cocky and he says to me [...] ‘I think I will de-sensitise you to [x]’. And I sat there shocked, I says, ‘excuse me pal, you de-sensitised me to [x] six

months ago' [...] He [...]didn't even know I'd stopped the combination, he just knew nothing [...] you're just a number you know.

Her comments recalled those made to Crossley by members of the 'National Long-Term Survivors Group' concerning their rejection of medical authority and their scepticism with respect to medical technologies and knowledge. Crossley terms this perspective 'empowerment'. In her analysis:

this understanding of the experience of chronic illness celebrates the authority of the patient in living or dealing with his or her illness, challenging the authority of professional technical knowledge and competence [1998, 511].

She also identifies:

a commitment and confidence in the experiential or 'subjective' knowledge of one's body and self, often related to rejection or scepticism about the 'objective' knowledge of science, medicine and other 'outsider' or professional groups [1998, 518].

In conclusion, most of the respondents emphasised the importance of employing strategies to protect their physical health. To different degrees, most respondents also wanted to assert control with respect to the medical profession, an institution with considerable influence in their lives. Equally important to the respondents' sense of control, however, in the light of their financial and material circumstances, were their dealings with the DSS and local housing authorities.

The Importance of Economic and Material Resources to Post-Diagnosis Identity

The respondents' fears and concerns relating to their economic and material circumstances were a major theme of the interviews, recalling Huby et al's finding that in Edinburgh:

problems associated with acquiring adequate housing and income seemed to dominate the life of the [service] user population. [1994, 28; also see Porter et al: 1995, 6].

Similarly, the authors of the Positively Women study in London, emphasised that:

for the HIV-positive woman, the social, [psychological] and practical implications of living with HIV or AIDS may at times be more pressing than the medical features of the disease [1994, 38].

In this study, all the respondents were in receipt of means-tested benefits, and all lived, or had lived, in social housing. These respondents' lifetime socio-economic circumstances and expectations were very different to the more middle class respondents interviewed in several other studies in the developed world [Carricaburu and Pierret:1995; Ezzy et al.: 1998]. Unlike the respondents in these studies, none of the women was concerned with the loss of insurance or private health care policies, nor had they experienced substantial reductions in income since diagnosis. In contrast, all the respondents were obliged to obtain basic resources, such as income, and often, housing, through interactions with powerful bureaucracies. These included the Department of Social Security [DSS, now known as the Department for Work and Pensions] and local authority Housing Departments.

The practical significance of, and difficulties involved in, the respondents' interactions with these bureaucracies have been discussed by several writers [see Huby et al. 1994]. This section will focus, however, on the crucial importance to the respondents' identities of their material health and of their interactions with these agencies. Some of the literature hints at this:

The divisions between health and social services, and between the public, private and voluntary sector, do not reflect the reality of people's needs and lives [...] while most of the research and development projects included in this synthesis concern user involvement and social service authorities, the involvement of people in decisions made by health, housing, voluntary and private organisations is just as important [Lindow and Morris: 1995, 23].

Further:

control over the assistance that is required to go about daily life is crucial [...] to the concept of independent living [Morris: 1998, 167].

Interpreted in this light, the highly emotional content of the respondents' answers to my questions concerning benefits and housing matters are revealing. The fear, anger and humiliation involved in the respondents' interactions with the DSS were a recurrent theme of the transcripts. Housing was another highly charged issue. In several instances, responses to my matter-of-fact first interview question 'have you moved since your diagnosis?' surprised me by their length and emotional content. For example, R7 focused on her early family history, particularly her father's absence and her mother's long illness and death, which she saw as the seed for her involvement with drugs. R10 was reminded of her husband's death and R2, of her brother's death. Moving house, in particular, was often associated with distressing events or circumstances. R2's brother's death had left her homeless, and several former drug users had moved on countless occasions. R1, on the other hand, related more current concerns: she was considering a move because of a breakdown in her relationship with a daughter and neighbour. Housing moves, therefore, seemed to symbolise the many different losses and difficulties experienced by these respondents in their lives. Their interactions with the gatekeeper bureaucracies to these resources could only have an important influence on their sense of self.

Maintaining Financial Circumstances: Interactions With the DSS

The influence of the DSS over the respondents' financial circumstances was almost total. To a large extent, DSS decision-making determined the respondents' level of income, and, therefore, their ability to deploy many strategies to protect their health, for example by heating their homes and buying nutritious food. The role DSS decision-making, and the consequent receipt of certain benefits, could play in increasing the respondents' sense of control over their situation is discussed in the first section.

The Crucial Importance of Disability Living Allowance [DLA]

As noted, all of the respondents were in receipt of the basic, means-tested benefit for those not expected to work, as a result of illness or child care responsibilities: Income Support. The significance of receiving DLA, in addition to Income Support, is evident from the comparison below.

At 2002-3 Income Support rates, a typical single parent, with one child aged under sixteen, would receive £127.35 a week, composed of an adult personal allowance, an allowance for a child aged under sixteen, a lone parent premium, and a single disability premium. The latter element of £23.00 a week would be added if the mother had been on Income Support for illness-related reasons for the previous year. Receipt of Income Support would also entitle her to full Housing Benefit and Council Tax Benefit, and 'passport' benefits such as free prescriptions and school dinners. Despite recent increases in the level of children's allowances, this level of income is extremely low, and was similar at the time of the interviews.

All the respondents, except R6, were, however, in receipt of some level of DLA payments. Since DLA is not counted as income for Income Support purposes, it does not affect receipt of Income Support, Housing Benefit, or any of the passport benefits. The nine respondents who were receiving the high rates of both the care and mobility components of DLA could therefore count on £95.55 per week on top of their Income Support. In addition, a severe disability premium of £42.25 per week would be added to their Income Support entitlement, a total of at least £265.15 per week.

Several respondents had lived on basic Income Support rates for years. Receipt of the higher rates of DLA had more than doubled their incomes. An irony of their situation, therefore, was that several respondents were much better off financially, and in several respects had a greater level of control over their material circumstances, than prior to their diagnosis. As R5 put it:

[my income's] really went up, it's just really went up.

R6, who was not in receipt of DLA, wistfully described its effect as:

really just a quality of life.

R7 keenly appreciated DLA in terms of the control it allowed her over her finances, after years of living on basic social security benefits, running up debts. In the following extract, her great surprise at ever being in a position of control over her

finances is evident, in her use of the present tense, as highlighted, to describe her former financial situation:

it's made a big difference over from when I used to just to get my Income Support [...] I've got a car, [...] for the mobility ehm, [...] I feel like I'm getting there, whereas *usually I've* never any money.. and *I'm* always like need this, need that ehm.. but things seem to be running alright the now. I just hope it stays that way. But I think it's just that I'm not used to having all this money.. [...] I usually just *try* and scrimp on whatever they give you every week - I think it's about £80 or something but now I'm maybe £200 or so [...] cos I got into catalogues and that so when I was on £80 everything was going out on bills and that ehm and I couldnae live.

R2 and R3 had used the extra money to move into private-rented accommodation, after the local authority had placed them in unsuitable accommodation. Instead of being dependent on the local authority's allocations, DLA had allowed them to exercise a greater level of control over their living environments.

Another example of the way in which receipt of the higher rate mobility component of DLA could radically increase the respondents' control over their environment was the possibility of leasing a car, instead of taking a monetary payment. Several studies have shown that lack of transport can present a major barrier to service use [Hull-York Research Team: 1993, 45-6; Positively Women: 1994, 4, 48]. R10, who was appealing the decision not to award her the mobility component, emphasised that her access to HIV services would be facilitated by access to a car. She had recently been forced to decline one service offered to her, as she could not get there and back by public transport within school hours. This problem was also mentioned by R1 and R12. R5, who also had no access to a car, complained about the cost of taking taxis to medical appointments.

Obtaining the higher rates of DLA was crucial, therefore, to the respondents' control over their financial and material circumstances, as well as to their physical condition, and to their self-perception as independent beings, able to make decisions to protect their own health. The importance of financial health is further illustrated in the

following section, which notes the respondents' intense fear of threats posed to their receipt of DLA by changes in government policy.

Threats to the Respondents' Material Security: the Benefits Integrity Project

DLA had provided several respondents with what was, for most of them, an atypical level of control over their material and financial circumstances. Moreover, initially, DLA had been awarded to these respondents for 'life,' providing them with an assurance that this situation would continue. The introduction of the Benefits Integrity Project [BIP] undermined the sense of security provided by 'life awards', by subjecting their holders to, often annual, reassessments of their eligibility [see Allirajah: 1997]. This was a body blow to many respondents, whose ability to employ strategies to maintain their health, for example, depended on their continued receipt of this benefit.

The anxiety of many respondents with respect to this 'review' process was palpable:

One of the things that did make me unwell this year was back in April they were talking about taking us off the DLA, people with the virus, and making us go back to work and I just like totally panicked ehm, ... there was a bit in the paper about it, and I was worried sick [...] I don't know what I would do if I lost my DLA ehm.. I mean that's what keeps my home warm and furnishes it and everything (R4).

As discussed, R2's second interview was dominated by her visceral sense of losing control in several spheres of her life: her health, her position as a mother, as well as her financial situation. She had been notified of a visit by a DSS official in the following week, and was:

stressed to death about it. I even went up to the City. I said to them, how the hell on one hand when I was first diagnosed I get it for life [...] until the year [...] 2034 [...] I remember looking at it thinking 'God, 65, I'll never reach that, I shouldn't have a problem' ken [...] And now all of a sudden they have this right to come in and question it because they think the triple combination is the cure.

She associated any ability she had to control her health directly to her DLA:

I use my money to eat well and I buy extra vitamins and I'm into alternative therapies [...] If they take that money from you therefore you cannot do the things that's keeping you well.

In her view, the stress created by the review had affected her health, and fears and suspicions provoked by it permeated her interview. She was angry that her confidentiality had been breached by a neighbour opening a letter sent to the wrong address. She had also accused her consultant of passing on information to the DSS, and wondered if a neighbour had denounced her to the benefit fraud hotline out of spite.

The generalised climate of insecurity created by the Benefits Integrity Project, among those respondents receiving DLA, was illustrated by the following exchange, between R3 and R2, as to the criteria the DSS might be using to remove recipients' benefits:

(R3) I think people like C would [lose it] because [...] he's only been diagnosed a few year. (R2) But what they're doing because long-term survivors have lived as long, they'll just cut them off. (R3) I dinnae see the sense in that because R got awarded his and that tells me that [...] if you're maybe in stage 1 or 2 or 3 of HIV then they'll take it off you, but if you're in stage 4 or 5 ..you'll no lose it [...](R2) I'm stage 4 (R3) I think 4 and 5'll no get touched.

R2 was not convinced, however:

what they're saying is that you're on the combination therapies, it'll make you live longer. So they're trying to get it to 4 as well. They'll end up killing us.

Like R2, R11 and R9 had become concerned that the success of their efforts to maintain their health, for example their attention to diet, their ability to keep their homes warm [see Huby et al.: 1995, 69] and in particular, their commitment to combination therapies, would be used against them to remove their entitlement to DLA:

My partner started combi therapy when he was really ill and they stopped his DLA. He's down to the basic £40 a week, because he's on combination therapy. [...]

You have all your side effects [...] and he can't work, and it's ridiculous. So he's to wait on an appeal (R9).

R11 also complained that combination therapies were viewed as a 'cure', despite the fact that the long-term effects of the therapies were unknown. The fear engendered by the BIP was such that the respondents seemed to view this process as a deliberate 'catch 22' created by the DSS to the potential detriment of their health. It was clear that this fear was exacerbated by the respondents' previous dealings with the DSS, which had resulted in a chronic mistrust of the organisation. Most viewed it as a compassionless, arbitrary bureaucracy, placing obstacles in the way of their attempts to protect their health. As R2 put it:

they've nae compassion in their bones

The Respondents' Fear of the Decision-Making Power of the DSS

In the light of the influence of this organisation over the respondents' lives, it is significant that only one woman was complimentary about the DSS, two others describing it, non-committally, as 'fine'. In contrast, most respondents highlighted the obstacles posed by it. For example, the effort involved in completing the long DLA forms, so crucial to the respondents' well-being, was mentioned by 6/12 women.² R4 indicated that, while she was happy to complete other claim forms, she always sought help with DLA forms, regarding them as set up to 'trick' the claimant.

Whatever the effort put into filling in the forms, many respondents also perceived the DSS decision-making process to be arbitrary, having been turned down for benefits awarded to others in similar health. R3, R4, R8, R10, R11 mentioned the social fund; and R2, R6, R7, R9, R10 mentioned DLA in this light. R6's decision to abandon an attempt to obtain DLA was influenced by her conviction, shared by several other respondents, that her claim would be hopeless. In her view, the attitude of the DSS to people with HIV was considerably less sympathetic than in the past:

you're not high enough priority [...] even if you've like a medical letter.

² As a former social security benefits solicitor, I found this complaint very understandable. I had to set aside three hours to fill in an application with a client. Further, clients were advised that their claim was much less likely to succeed without experienced help.

Similarly, several service providers I interviewed criticised the fact that the DSS tended not to recognise the chronic fatigue experienced even by asymptomatic HIV-positive people.

Reviews or appeals to the Independent Tribunal Service were at that time the primary means of challenging DSS decisions. Their use might provide one way of asserting a degree of control with respect to DSS decision-making. R7, for example, did liken the appeals process to a battle, a way of taking the DSS on:

I'm just really happy that I got my money [..]. I mean that made me quite happy cos I'd been *fighting* for it for so long.

In general, however, the appeals process was not perceived as a means of influencing the decision-making process, but as a lengthy, stressful and demeaning drain on mental and physical health. R9 and R10, respectively, described the appeals procedure as:

outrageous ... ehm demeaning, draining.

embarrassing, like begging.

Two respondents had given up appeals because of this perception. At the time of her second interview, R10 had also missed an appointment with her advice worker regarding her appeal for the mobility component of DLA:

I think [..] I maybe avoided it in my own way. Just the thought of having to go through all this.. och it's a bit heavy.

In the absence of advice, she had also wrongly assumed that she would have to be medically examined at the appeal hearing.

Several respondents' concerns reflected their perceived powerlessness in relation to disrespectful, insensitive or improper exercises of power by DSS workers. R9's complaint related to the conduct of a Benefits Agency Medical Service [BAMS] doctor:

[he came] to do the exam in the house to question me [...]. But he was really facetious. He was very 'oh I presume you got this from sex' and things like that. And I just thought 'get out of my house'.

R3's problems also related to one individual:

it was like a personal thing .. between the guy in the social security and me And he withheld my money for something like five months before he actually sent me a giro that I was entitled to.

Other eligibility rules for benefits, as well as the process by which they are enforced by the DSS, caused some respondents to be fearful, and influenced how they organised their lives:

I hate the place am I allowed to say that? (S: oh yes say anything you want) [..] they just [...] really frighten me. I don't mean they frighten me but just what they can do to me now, they can take my book off me [...] just the thought of having no money really frightens me.. cos I haven't got any put aways.. well there is but that's the bairns' money, it's really no mine [...] I mean I know what it's like to toil and I dinnae really like to go back to that but I always feel, that they've got something over you [...] they've got a hold over you like (R7).

She and her partner paid careful attention to the number of nights they spent together per week, in order not to be considered cohabiters:³

he used to stay with me..but they're gonnae be catching everybody that's staying with their partners [..]. Every time the door goes and if he's sitting during the day I'm like God, I hope it's no.. cos I've had them once at 11 o'clock and [..] I thought it was the postman and I just opened the door and there was like the social security.. all like 'don't cash your book, hand it in' [..] Cos they'd got a phone call and they were really quite aggressive and [..], it was really quite frightening. It was two men that came to my door and really since then I've really been quite paranoid about them.

³ The cohabitation rules assume that each partner contributes to the household, and that such pooling of resources means that cohabiters require proportionately lower levels of means-tested benefits, such as Income Support, than the single claimant. Further, a cohabitee who works can eliminate the other partner's benefit entitlement. *Social Security Contributions and Benefits Act (1992) s.137(1)*.

In conclusion, the respondents' overall interactions with the DSS detracted from their sense of control over their financial and material environments, and ultimately their ability to gain a measure of control over their health. While DLA could make a huge difference to the respondents' finances, the BIP and subsequent policy developments had undermined any sense of security associated with the receipt of this benefit. This insecurity with respect to their material circumstances, and ultimately their health, was further reinforced by the respondents' interactions with various housing authorities.

Interactions With the Housing Authorities

The particular significance of housing with respect to the respondents' sense of self, and its association with previous losses, has already been noted. In the light of their inability to work, and lack of independent finances, most of the respondents also had to engage with local authority housing departments and housing associations to obtain a suitable home. At the time of their interviews, seven respondents were council tenants (three of whom lived in specialised supported accommodation), and three were housing association tenants. Only two respondents had by-passed the need to deal with these organisations by becoming private tenants, although this strategy raised its own problems.

Half the respondents were happy with their housing. Half were not, however, and several commented on the difficulty of maintaining their health in inadequate housing circumstances, a concern also emphasised in the literature. For the Hull-York Research Team:

housing is [...] a key service for clients who are HIV-positive [1993, 134],

pointing to the need for extra rooms for carers, and for ground floor flats in safe areas, close to amenities. In turn, Firth [1987, 24-5] and Positively Women [1994, 43-5] raise many housing problems experienced by HIV-positive people, including damp, cold, vermin and sub-standard bathroom and kitchen facilities, in both public and private sector tenancies.

Several respondents' concerns related to the unsuitability of the flats they were allocated. R9 had been placed in a damp flat on the third floor, although her council had rectified this quickly when she put in for a move. R10 and R11 found it difficult to access public transport links, and therefore services, from their houses. R1's housing problems seemed even more fundamental in terms of maintaining health. She had moved into her council flat three years previously:

When I moved in I was told not to decorate because they were going to be putting central heating in and double glazing [...] I moved in in the April and they said by September we'll be doing the central heating [...] They didn't do this until this year, three years later. So I'm now in the process of trying to make it a home [...] and we've actually got windows that work.. the heater's set up and it's going to be our first warm winter ...[.] I've never had a house with central heating.

Security was also a major concern. For example, R1 had been broken into five times and held up at knife-point in one flat. R7 could not believe her luck with her current council flat after previous experiences:

Niddrie [...] I hate the place [...] I'd left the carpets in that one, I was gonnae go back [...] and on the Sunday we moved, and on the Monday I went to see if there was any mail, and they'd broken in and stole the carpets and stole the light-bulbs out the house [...] and I thought oh God... please don't put me in anywhere like this again.

Two respondents, both in receipt of high rates of DLA, had decided to bypass these problems in the public sector, by moving into private tenancies. R2 explained this decision at length:

I was made homeless [...] I was given a house [...] bang, smack in the middle of a drug environment.[...] and their attitude was the points system's there ...[but] if you've got your DLA, and your consultant's telling you that you are dying basically, you should get top medical points which overrides anything, but [...] they stuck me in the first floor flat of a damp council house and all that just led to my breakdown last year. So I've basically approached them again and [...] basically they said to me I'd have to wait. And I was trying to explain to them that time wasn't on my side [...] but they couldn't promise me anything at all whatever.

R3 had taken the same step, after having been offered a housing association property:

it was like a rabbit hutch, [...] tiny. I wouldnae even have been able to be sick in the toilet privately.

Both were happy with their current accommodation. The move to the private sector, however, had several pitfalls, including the lack of security of tenure. Both women were anxious that their annual leases might not be renewed. With this in mind, R3 was concerned that her landlord should not learn of her diagnosis.

Another concern was the non-transferability of tenure in the private, unlike the public, sector. R3 worried that if she died, her son would not be able to stay in her house. Both of these respondents were also acutely aware that housing benefit did not fully cover their rents, and that they could only afford their current accommodation by using money from their DLA payments [also see Firth: 1987, 12-13]. Their ability to pay for their improved housing circumstances was, therefore, also dependent on the success of their DLA reviews, a further reason for their anxiety about the Benefits Integrity Project.

All the other respondents remained in public sector accommodation. The likelihood of their obtaining suitable accommodation was severely constrained by the lack of investment in the public sector and reduction in the housing stock [Murie: 1998]. The respondents' worries relative to their housing conditions were further exacerbated by their lack of control over local authority housing departments' and housing associations' allocation processes. As discussed, most respondents had been offered accommodation inappropriate to their needs, despite being awarded medical points in light of their condition. All were acutely aware of their limited margin for manoeuvre in this situation: potential council tenants may only refuse one offered tenancy before losing the right to be re-housed.

Similarly, several respondents emphasised their difficulties dealing with the rigid procedures of housing authorities, as well as the energy and patience required to negotiate the delays and uncertainties of the process:

I kept phoning up the local housing office [..] and telling them [...] that they'd have to move me, that it was gonnae lead to my death if the stress didnae stop. But they hadn't got the stock of houses, that's what they kept telling me.

R5 said she had waited eleven years to be housed, while R11 had run the risk of refusing unsuitable council properties before obtaining a housing association flat. R8's experience was similar:

I put in for a move- oh it's not been that long really, three and a half years ago ehm and I just let it go for so long and then [...] Easter ehm I got a letter from [agency] just explaining how things work [...]. At first I got second priority and I went up to the Housing when I got that and [..] I says to them so is there any houses available in And they says to me you'll never get a house there (R8).

R7 highlighted the difficulties inherent in a points system, where tenants' health can change rapidly. By her second interview, she was experiencing fatigue and breathlessness, and wanted to move to a ground floor flat. At the same time, she worried that the stress of a move would affect her health. Similarly, a GP I interviewed criticised the fact that maximum housing points could only be obtained once tenants had developed quite serious conditions. Requesting a change, obtaining letters from their GPs, and actually moving drained energy and increased stress at a difficult time [Huby et al.: 1995, 47-8]. Some of the points made above, with respect to the potential for the manipulation of the patient-GP relationship, are also relevant here.

As noted, three respondents had moved into specialised supported accommodation. While R12 was very happy with this arrangement, the others raised concerns relating to their control over their living circumstances, relating to the obligation to have a keyworker. R6 emphasised her efforts to persuade her keyworker to come to her home less frequently. R5 complained that her keyworker badgered her to talk about dying:

she just persisted...[....] and I used to have to say to her again and again I don't want to speak about that...you're here to talk about what I want to speak about, not force issues that you want to talk about.

She also disliked the fact that the keyworker had a key to her property, seeing this as another form of intrusion:

I hate it here [...]they've got keys for your house [...]They've said it's just in case anything happens to me and they cannae get in. And I says to them [...] 'if anything happens to me one of my family'll [...]find me before you do'. [...]It's just an excuse to have a key for your house.

For these respondents, therefore, supported accommodation detracted from, rather than enhanced, their perception of control over their living environment. One of these respondents moved out of her supported accommodation tenancy soon after her interview.

All of the respondents were largely dependent on the DSS and housing authorities with respect to their own and their children's material and financial circumstances. Unfortunately their interactions with these powerful, rigid agencies were often time-consuming and stressful. Despite the enormous difference obtaining DLA or appropriate housing could make to their feelings of security and to health, most of the respondents' interactions with these agencies undermined their feelings of control over their situation.

Conclusion

Reading through the respondents' transcripts, I was struck by recurrent references to the need to 'fight' to establish and maintain control over their health and material circumstances. The respondents repeatedly returned to these concerns throughout their interviews. In the light of the damage to their immune system and their historically fragile economic circumstances, the practical significance to the respondents of these issues is easy to understand. The respondents perceived all of these areas of their lives to be inter-related. Once any kind of control had been obtained with respect to any of these matters, the respondents' perception was that it needed to be staunchly defended. A breach in any of these defences could lead them all to crumble.

A good example of the inter-relationship between these issues was the respondents' anxiety as a result of the threat posed to their life awards of Disability Living Allowance (DLA) by the Benefits Integrity Project. DLA had made a huge difference to the respondents' ability to control their material environment, and to take further measures to protect their health, for example through buying healthy food, vitamin supplements, heating their homes adequately, and selecting their own accommodation. The idea that they might lose their DLA was, therefore, a source of great anxiety to the respondents, some of whom were experiencing ill health.

The respondents' efforts to maintain a sense of control in these areas were also intrinsically linked to their concern to maintain their post-diagnosis identities as mothers living their lives normally in spite of their diagnoses. With respect to their health, the employment of strategies to obtain some purchase over their condition, relates, in part, to their concern to live their lives as normally as possible. To some extent, the latter may represent a desire to maintain a connection with the past. It may also reflect the moral imperative, emphasised by Cornwell [1984], examined in Chapter Four, of being seen to get on with things, and not to moan.

Another important illustration of the relationship between strategies to maintain health and the respondents' post-diagnosis construction of identity as normal people was the high value they placed on asserting their own independence, and on making their own decisions. They expressed a sense of self and values, similar to those examined by Crawford [1994] in terms of the modern emphasis on individual responsibility with respect to health. The importance to the respondents of asserting evidence of this responsibility was illustrated throughout their interviews.

This association between the respondents' sense of control, their post-diagnosis sense of identity and independence was further underlined by their interactions with medical professionals. Most respondents viewed the medical profession as a crucial resource with respect to the preservation of their health, and several enjoyed good relationships with their consultants and other medical staff. However, most respondents were also concerned to influence the medical decision-making process, and to obtain sufficient information from their doctors to make their own informed choices. Some respondents' commitment to exercising agency with respect to their

interactions with the medical profession went further than this, however, adopting the language of empowerment in relation to treatment decisions, and questioning the 'learnt' expertise of these professionals as compared with their own 'embodied' knowledge.

The importance of exercising some agency with respect to medical decision-making was perhaps underlined by the lack of such opportunity in their interactions with the DSS and housing authorities. The significance of these bureaucracies, as gatekeepers of such crucial resources, to the respondents' sense of control over their health and material circumstances was evident in their emotional accounts of their interactions with these agencies. Many respondents felt humiliated by these interactions, and fearful of the agencies themselves.

The respondents' use of medical services, the DSS and the housing authorities was viewed as unavoidable in their battle to obtain a sense of control over their health, medical treatment and material circumstances. The emphasis placed by the respondents on these issues, and the inter-relationships they identified between them, suggested the importance of these issues to the maintenance of post-diagnosis identity. For example, a sense of control was closely associated with living a normal life and with asserting individual over decisions and circumstances affecting them. This chapter has therefore further underlined the importance of issues of identity to understanding service use. In the next chapter, the respondents' use of voluntary services will be explored in the light of their concern to maintain a sense of control.

Chapter 9: The Effect on Social Service Use of the Respondents' Concerns for Control

In the previous chapter, I emphasised the importance of establishing and maintaining a sense of control for the respondents' maintenance of a coherent post-diagnosis identity. The respondents' concern to maintain a sense of control evolved in response to their fears of losing their health, material resources, and decision-making power over these issues and their medical treatment. All of these matters were perceived to be inter-related. The respondents' emphasis on preserving their sense of control also reflected a determination to live their lives as normally as possible, and to assert a moral response to their diagnosis, by not giving up, but continuing to 'fight' against the potential implications of their diagnosis.

The importance of a sense of control to the respondents' post-diagnosis identities was also emphasised by their emotional reactions to interactions with powerful professionals and bureaucracies who determined their access to basic resources such as treatment, housing and income. While the respondents were, to a large degree, 'captive' users of these agencies [Lindow and Morris: 1995, 39], this was not the case with respect to their use of HIV-specific social services, such as self-help groups, residential facilities or agencies providing practical help. In this chapter, I will argue that the use of these services can only be understood in the light of an understanding of the importance to the respondents of maintaining a sense of control.

Drawing on literature on service user involvement [Jack, ed.: 1995; Lindow and Morris: 1995; Barnes and Walker: 1998], it will be argued that the respondents' individual perceptions of how a particular service might enhance or detract from their sense of control is an important influence over their use or non-use of that service. Some services were almost universally seen as enhancing the respondents' sense of control. These included services providing practical assistance, and those helping to navigate the social security bureaucracies. The respondents' attitudes towards other social services, particularly those providing meeting places, referred to in this study as 'social space' agencies varied, however, between respondents and over time. 'Social space' agencies could provide important resources for

respondents to meet and develop their post-diagnosis identities as people living normally in spite of their diagnosis. For others, ideas of empowerment and user participation in services, particularly self-help agencies, provided an opportunity to further develop their identity of being in control. In the light of many HIV activists' focus on these issues, they will receive particular attention in this chapter.

Use of Social Services to Facilitate Control Over Basic Resources

In the previous chapter, the importance to the respondents' self-perception of their lack of control over the decision-making processes of the DSS and housing authorities was emphasised, as were their fears with respect to the fragility of their material circumstances. The respondents' great appreciation of services helping them to negotiate the social security system, was, therefore, unsurprising.

At the time of the interviews, these services were provided by local authority advice workers running regular drop-in clinics at HIV-specific voluntary services. All but one of the respondents had used specialised advice workers, on several occasions, to prepare applications and, sometimes, to present their cases at appeal. The respondents' interviews contained many references to the names of two such workers, whose efforts were seen as crucial to successful applications for benefits, and particularly to negotiating the complex and lengthy process of applying for Disability Living Allowance [DLA].

Huby et al. emphasised the need for this type of service in their research. In its absence, they found that many respondents had adopted a strategy of asking for benefits information from all the professionals with whom they had contact. The professionals themselves saw this as an 'illegitimate' use of services [1995, 39, 45], while some of the medical professionals' accounts [recorded at 1995, 58] suggested that they under-estimated the complexity of the benefits system, and had given incorrect advice to their patients. From the point of view of service users, therefore, this strategy would seem to be an understandable, if misguided, response to a highly significant gap in service provision. An Edinburgh SWD representative I interviewed indicated that the concerns raised in Huby et al.'s study about the lack of

provision of benefits-related information had been taken on board, leading to the development of the services so appreciated by the respondents in this study.

At the time of the interviews, however, it seemed likely that these improvements in service provision would be undermined. The Benefits Integrity Project, discussed in the previous chapter, increased the pressure on local authority and voluntary services.¹ One SWD representative I interviewed stated that recent local government spending cuts had focused on ‘non-frontline’ services, the definition of which included services providing benefits advice. In fact, the transcripts suggested that local benefits advice services were understaffed and under-funded. One practical example of this was the non-replacement of the City of Edinburgh Advice Shop’s specialised HIV benefits worker during a period of sick leave. Several respondents emphasised the problems this had caused them.

Also of concern, therefore, is the lack of awareness and availability of similar services in relation to problems with housing. Six respondents had never received any housing advice, and several indicated they were unsure where to obtain it. The rest of the sample had approached non-specialised sources, including social workers, for advice. One respondent thought there was a specialised worker at the HIV-specific agency she used, but another thought this service had been cut. Only one respondent had heard of the Housing Advice Centre which provides advice for housing association or private tenants, and none had used the legal advice and assistance scheme to obtain free legal advice in respect of housing transfers, although all were financially eligible for this scheme.

The issues explored in this section strongly suggest the importance of services assisting with access to material resources to the respondents’ sense of control. The respondents saw their financial and material circumstances as crucial to their capacity to maintain control over their health, and to make their own decisions as to how to do so. In the following section, the respondents’ use of social services to try to maintain control over their physical and emotional health will be examined.

¹ Personal communication with CAB tribunal workers commenting on the increased workload due to the Benefits Integrity Project and other review programmes eg of Incapacity Benefit.

The Use of Social Services to Maintain Control Over Health

The Role of Social Services in Maintaining Physical Health

In both Edinburgh and Glasgow, agencies staffed by volunteers provide practical help to service users. Typically this help includes babysitters, home-helps, gardeners, decorators and lifts. Most respondents had used these services: 8/12 respondents had used them in the six months before the first interview, and 4/7 in the period between the two interviews. As previously discussed, these services were perceived as entirely compatible with living a 'normal' life, partly because their use involved no contact with other HIV-positive people. However, the use of these services could also enhance the respondent's sense of control, and in her interview, the manager of the Edinburgh agency specifically described its philosophy as aimed at increasing service users' sense of control over their situation. If, therefore, the users' priority was to spend uninterrupted time with their children, a home-help might be provided. If, on the other hand, respite from the children was desired, a babysitter might be appropriate.

The provision of lifts was particularly important to those respondents who did not have cars. As Torgerson and Donaldson [1994] point out in their economic analysis, time and transport are crucially related to the service use of people not in professional jobs. Several respondents in this study, including R5, R10, R11 and R12, emphasised their frustration where volunteers were not available when they needed them to take them to hospital or other services. Since these respondents felt they could not afford taxis on a regular basis and were tired by the use of public transport, not being able to get a lift affected their choices as to the other services they might access to maintain control over their health.

Such services included the alternative therapies primarily provided through 'social space agencies'. These therapies, including massage, raiki and aromatherapy, were used by 7/12 respondents. Some of these respondents identified these therapies as the most important services for them. R10 was very disappointed that her inability to obtain lifts on a regular basis meant that she was unable to take up the offer of an aromatherapy course provided through one agency. R1 complained that she could

not access these services by public transport and still be in home for her son finishing school. Like R10, she did not live close to a direct bus route to these services.

The Effect on Social Service Use of Concerns to Maintain Emotional Health

In the previous chapter, the respondents' everyday strategies to protect their emotional health were also discussed. For some respondents, the use of 'social space' agencies was a further important strategy to protect their emotional health. In contrast, other respondents emphasised the importance of limiting the space taken by HIV infection in their thoughts with respect to their use of these services. For them, it was important to protect their emotional health by avoiding the over-use of these services.

Several writers have explained the popularity of self-help or support groups in terms of giving the users a vital means of feeling that they have control over their health [Offer: 1999; Barnes and Walker: 1998]. For Offer [1999], the use of these groups compensates for the tendency of professionals to under-estimate the social effects of serious diagnoses.

The respondents' comments emphasised the strength they drew from meeting others in a similar situation. R8, for example, liked self-help organisations because:

you can just sit and talk to one another.

R7 had gained reassurance and confidence from the fact that, when she talked at meetings of HIV-positive mothers, the other mothers listened to her without interrupting.

However long they had known the HIV-positive people they met at agencies, the relief of contact with others with the same condition, for those feeling isolated and stigmatised, was emphasised by several respondents:

[it's] reassuring, you learn to like yourself again because you're not that different.
[....] It's helped me a lot. I mean I'd still be sitting at home in bed or by myself having no kind of life at all. I'd just alienate myself from everybody (R12).

The respondents' comments suggest the particular importance of such reassurance to people diagnosed with such a long-term, uncertain and stigmatised condition. Damen et al. identified this concern as perhaps the primary reason why the survivors of breast cancer they interviewed used self-help groups:

the need to talk to women who had experienced the same thing was repeatedly mentioned [2000, 345].

R3 expressed the benefit of using these services to her sense control, most directly:

you really need [...] to share this with other people how you feel and realise that there are other women who are feeling the exact same way as you [...] you're not alone. And if you come to [a 'social space' agency] you'll meet people like that and feel better about yourself.

For some respondents, however, the over-use of these services could present a threat to their control of their emotional health. R4, in particular, emphasised that her life, and her relationship with her daughter, should not be dominated by HIV infection and its potential implications. This concern had influenced her minimal use of social space agencies. As she put it:

I don't know if that keeps me away from the services, thinking if I don't go to them then I'm not thinking about it...Cos, to me, there's a time and place to talk about what's wrong and you have to know when. If you talk about it all the time then it means I'm living with it instead of it living with me. I don't want it to be the only conversation in my life, you know I want a *normal* life, a *normal* conversation.

Her determination to control the space taken up by HIV infection in her thoughts was, therefore, closely linked to her concern to maintain her identity as someone living normally in spite of her diagnosis. Her strategy of maintaining control excluded the use of social space agencies, historically, and at the time of her interviews. R4 was, in fact, the respondent who reported the least use of such services. Unlike several respondents, often former drug users, who did not want any workers to come to their home, she also expressed a preference for home-based

practical services. At home, she felt more in control of her interactions with workers, able to smoke or to make a coffee as she wished.

Struck by R4's and others' first interview comments, I incorporated a direct question into my second interviews, asking the respondents to consider whether there was any relationship between their concern to control their thoughts about HIV infection and their use of social space agencies. The transcripts revealed that, for several respondents, unlike R4, some use of such services was compatible with this concern, although it was important not to use these services too frequently or to become too dependent on them. R6, for example, made similar comments to those of R4, but did use social space agencies sporadically. The following excerpt from R10's second interview suggested that she had also thought a lot about the relationship between the level of her use of these agencies, and the need to protect her emotional health:

I think some people let it [take over], in fact I know lots of people like that ..[...]. But I know where they're coming from, because I've been there myself with my husband [...] eventually it's like you start to think of that [a service] as your family eh...sometimes I think it can be a bad thing (Yes?) Aye, I think you can let it overtake everything else.

Like R4, R10 associated this concern with her desire to live 'normally':

So I think that's really important to try and keep it [...] and be normal as well

Her view was further influenced by recent medical developments which suggested that she was likely to live longer than had originally been envisaged. With this in mind, she reasoned:

I feel that there's no need for ...letting it overtake your life

Other respondents' answers suggested that the level of social space agency use considered to be compatible with their notion of control could fluctuate over time. Several respondents, who had been frequent users of these services, and had even been involved in committee work, had later decided to end this level of involvement.

R11, for example, emphasised that it was important to her that her friends did not always talk about HIV, and she had withdrawn from committee work:

it was definitely too much actually working because I did just as much as the paid workers, and it was just too constantly in your face.

For R5, this re-think related to her recent 'AIDS' diagnosis. She now felt isolated from people who were 'just' HIV-positive, saying of one acquaintance at a social space agency:

he's only HIV-positive, he's only had it three years, his health's fine really.

She expressed her need to withdraw from service use particularly strongly, after years of involvement:

I used to have a lot of gay men friends but I dinnae see as much of them....[...]maybe because things have changed for me and [...]I get tired quite easy [...]Some of them are just too heavy, and they just go on and on and on and on . [...]All they wannae talk about, [...]is HIV [...] I keep away from it cos it just can work the other way, it depresses you.

In conclusion therefore, for several respondents, their concern to maintain control over their emotional health by limiting the space occupied by HIV infection in their thoughts was an important influence over their use of 'social space' agencies. It is important to note, however, that this concern did not translate into identical strategies with respect to the use of social space agencies, and that the respondents' ideas as to the degree of compatibility between their need for control and their use of certain services could fluctuate over time.

For some respondents, however, the use of social space agencies was significant not only with respect to their sense of control over their mental health. Ideas of empowerment, and of participation in the running of services, had become very important to their post-diagnosis identity. These ideas have been emphasised by writers interested in self-help, including Jack [1995], as well as by HIV/AIDS activists in particular [Roy and Cain: 2001].

Participation, Empowerment and the Use of Social Space Agencies

Participation and Worker-Led Social Service Agencies

In the previous chapter, respondents' concerns with respect to their relationships with medical professionals were discussed, including their desire to exercise decision-making power with respect to their treatment. The effects on the respondents' self-perception of their lack of influence over the decisions of the benefit and housing authorities were also highlighted.

Issues of participation and empowerment were also important with respect to respondents' engagement with 'social space' agencies. Some of the respondents' interviews reflected concerns discussed in the literature with reference to different notions of 'service user involvement' or 'participation' and 'empowerment' [Barnes and Wistow, eds.: 1992; Lindow and Morris, eds.: 1995; Barnes and Walker: 1998; Mayo: 1998]. In the following sections, the ways in which the respondents' interviews touch on these ideas, in respect of both individual care planning as well as opportunities for influencing policy-making within individual organisations, will be discussed.

Concerns Relating to Decision-making Power Within the Client-Worker Relationship

In their analysis of the incorporation of the values of empowerment into practice, Barnes and Walker comment that:

most initiatives have focused on user involvement at policy level or service planning rather than input into service users' own care planning [1998, 202-3].

They criticise this approach, emphasising the need for a change in the way social professionals are trained:

[a] preparedness to loosen control and embrace users' own definition and solutions requires different skills from those which professionals may have been taught [1998, 202]

The importance of these issues to most respondents was evident in the interviews.

R4 explained her long-standing decision not to use social space agencies:

I like to do things my own way [...] I try and do what's best for myself you know, and everybody's different [...] You go to [agencies] and they have their ways of doing things that might suit the majority, but other people have different ways and [...] sometimes they allow you to use that way and other times they don't: it's like their way or not at all.

Unlike R4, R10 had started to use some social space services, after a long period of non-use. Initially, however, she had been wary of contacting such agencies for similar reasons:

for fear of them taking over, if you like.

Another strong indication of the importance of control over decision-making to the respondents' use of these services was provided by the vehemence of their 'off-the-cuff' reactions to the first interview flashcards. The respondents' reactions indicated that the agencies they most appreciated were not 'bossy' or 'controlling'.

R10, for example, made the following, uncharacteristically fierce, comments about an agency providing children's services:

strings attached, control life, treat you like a child, bossy. You don't trust them: I think there's always a doubt at the back of your mind, it's oh like, you wonder what they go back and say and all that.

She continued to use this agency out of concern for her son's welfare, but her own relationship with the worker was clouded by these perceptions.

R3 and R5 had similar concerns about a residential facility:

judgemental, don't trust you, nosey, treat you like a child, bossy, love to control your life, your drugs when they can (R3).

R5's response to the flashcards led her to make the following criticisms of her supported accommodation keyworker who, she felt, forced her to discuss issues she did not yet feel ready to address:

I said I didnae want to see her anymore because she'd just done the total opposite of what I wanted. Just was determined that she would counsel me about dying [...] And I says to her [...] I didnae want to talk about that because at that point I hadnae been ill[...] and she just persisted.

She felt that this worker was insensitive to the pace at which she wanted to deal with issues, a concern also mentioned by the representative of the Women's HIV/AIDS Network I interviewed.

These were not isolated examples, and reflected the respondents' lack of confidence in workers who, they felt, did not listen to them or treat them as adults. As a result, several respondents had stopped using some services. These concerns illustrate the relationship between the respondents' sense of control and values, discussed in Chapter 7, such as trust. For Barnes and Walker:

Trust is necessary both at the individual level, that is, in the relationships between the service user and the direct service provider, and at the institutional level. A reciprocal relationship of trust has advantages for both users and producers of welfare services [1998, 202].

In the following section, the relationship between trust in this sense and the respondents' sense of control will be addressed with respect to the opportunities provided for user involvement in deciding the policies of social space agencies.

The Respondents' Sense of Control and User Involvement in Services at a Policy Level

The respondents' interviews therefore emphasised the importance to them of their opinions being respected by workers, with whom they were often involved over long periods. Most respondents were upset by feeling that they had little control over decision-making within this relationship, and this affected their service use. There was, however, more variation in the respondents' accounts of the degree to which they wanted a role in decision-making at an agency level. Some respondents

preferred 'worker-led' organisations, while others, a minority, strongly advocated for self-help groups. For these latter respondents, their sense of control was strongly influenced and developed by ideas of empowerment emphasising the importance of user participation.

The following sections will discuss each of these different types of agency in turn, starting with concerns relating to user participation in worker-led organisations. It should be noted, however, that several respondents used both of these types of agencies. Further, the distinction between these types of agencies has been fluid in the HIV field, since many groups were started, ad hoc, in response to the progression of the epidemic, but have since become more professionalised [Roy and Cain: 2001, 430].

The Respondents' Sense of Control and Involvement in Worker-Led Agencies

Canadian activists, Roy and Cain, point out that various national and international documents have been produced by activists, emphasising the importance of the involvement of people with HIV infection in policy-making affecting them [2001, 421-3]. According to the, as yet unpublished, United Kingdom Declaration of Rights of People With HIV and AIDS [1991]:

people with HIV and AIDS should be fully involved in a working partnership with medical, health and social care workers and researchers to develop policies and practices which meet their medical, health and social care needs [in Roy and Cain: 2001, 422].

Roy and Cain also emphasise the numerous benefits of the involvement of HIV-positive people in the agency itself:

they bring a high degree of personal investment, motivation, dedication, compassion and commitment to the work. [...] The involvement of HIV-positive workers also helps organisations to identify new and changing needs [2001, 425].

The British literature on service user involvement has focused on analysing the different structures set up by agencies to involve users in policy-making. Many writers distinguish between 'consumerist' and 'empowerment' responses [Barnes

and Wistow: 1992; Lindow and Morris, 1995]. Barnes and Wistow describe 'consumerism' as making services more sensitive to the needs and preferences of users [1992, 8], and emphasise that such initiatives are often service provider, rather than service user, led [1992, 2; also see Beresford: 1992, 17].

Many of these writers emphasise that consumerism is the approach currently dominant among British social service agencies, but criticise it for:

produc[ing] an outcome detrimental to those with quiet voices; those whose needs are complex and shared with few others; and those who can command little public support and sympathy [Barnes and Walker: 1998, 206]

In response, Barnes and Walker elaborate their key principles of empowerment with respect to service user participation in agency policy-making, emphasising that empowerment should be viewed as a key part of the democratic process, concerned with developing service users' capacities to:

participate in decisions about the design, management and review of services [1998, 4].

Interestingly, they also relate the idea of empowerment specifically to that of control:

Empowerment should aim to increase people's abilities to take control over their lives as a whole, not just increase their influence over services [1998, 199].

At the time of preparing the interview schedules, I had not developed the idea of control, but had read some literature on empowerment [Jack, ed.: 1995]. As a result, my interviews with Edinburgh service providers included questions as to the means used by agencies to ensure user participation in the policy-making process. Their answers confirmed the prevalence of consumerist approaches to participation across the Edinburgh statutory and voluntary agencies. Only one organisation, which later became a self-help agency, had adopted what Barnes and Walker might term a truly participatory approach, in that a majority of the management committee members were HIV-positive people. This agency will primarily be discussed later in terms of the relationship between self-help and the respondents' sense of control.

In general, where HIV-positive people were present on management committees, they were in the minority, and could therefore always be outvoted. This approach was criticised by the representative I interviewed from the, now defunct, Women's HIV/AIDS Network. She commented that, as a result, women, in particular, had not been part of the policy-making process of Edinburgh HIV-specific voluntary organisations.

Otherwise, the primary method of soliciting users' views among the Edinburgh agencies was by means of questionnaires, mentioned by the representatives of four agencies I interviewed. Complaints systems and suggestion boxes were also characterised by some as a means of engaging with service users, while one agency representative emphasised the importance of 'informal' feedback. One agency organised several 'focus days' a year to obtain feedback from users.

Of all of the respondents, R4 was the least frequent user of services. She mentioned being happy to fill in questionnaire forms for an agency she sometimes telephoned for advice, but perceived this process as an obligation in return for the services she had received. It did not reflect a perception of contributing to decision-making processes within the agency.

None of the respondents viewed complaints procedures or suggestion boxes as an effective means of participating in agency decision-making. Some respondents had been involved in management advisory committees, with the aim of trying to improve services on behalf of fellow users, but none of these respondents thought that their participation in such committees had been effective. Ultimately, several respondents had come to perceive involvement in such committees as detracting from, rather than enhancing, their sense of control.

R8, for example, perceived that suggestions made by service users during the focus days organised by one agency were unlikely to be adopted. She had also been a member of a management committee at a residential facility. While she had tired of 'silly' complaints by residents, she was also convinced that the committee did not provide for effective participation by service users. Eventually she decided that the committee was:

just a waste of time [Why?] Because you went time after time and the same issues were brought up and up and up but nothing was ... done.

Involvement in this committee seemed to reinforce her sense of her lack of control over agency policy-making. R5, who had been involved in several committees, and even with setting up agencies, had come to the same conclusion with respect to this committee:

there's nae point in having a committee cos if the [...] the manager [...] doesn't want it, it doesn't happen [...] Really your opinion doesnae go for anything.

Some respondents' perceptions of attempts at user involvement in agencies were more cynical. R6 was convinced that user participation in services was, in fact, unwelcome:

They don't really like it when you voice your opinion, you're supposed to be victims, you know, you forget, we are victims...Not survivors, we are supposed to be victims.

Barnes and Walker suggest that committees have been used in cynical ways, commenting that:

inviting people to participate whilst failing to commit sufficient resources to finance adequate provision is a cynical exploitation of good will [1998, 205]

Similarly, R11 regarded the lack of publicity prior to a recent 'open' meeting organised by one of the major funders of HIV agencies, as a deliberate ploy to reduce service user participation.

R11 and R3 were both, however, more hopeful in respect of a new position being set up to talk to service users, as to the best way to consult them about the services they wanted. R11 was involved in interviewing prospective candidates for the position. Like R11, R3 interpreted this as a more genuine attempt to involve service users in the decision-making process:

they're gonnae ask people with HIV what they need, rather than telling us what they think we need.

The respondents who had been involved in such participatory structures were not, therefore, entirely cynical about the means provided by the agencies for participation. Further, participation remained important with respect to several respondents' sense of control. Unfortunately, however, the majority of the means provided to the respondents to become involved in agency policy-making, by the time of their interviews, had detracted from, rather than enhanced, their sense of control. As a result, many respondents had withdrawn from involvement.

More positive comments, in terms of enhancing their sense of control, were made by several respondents about a self-help group. This will be explored in the following section.

The Respondents' Sense of Control and Their Use of Self-Help Groups

The association between control, empowerment and the use of self-help organisations is noted by several writers. Damen et al. emphasise the view of self-help groups as people coming together to do something about situations about which they feel powerless, and review literature which indicates that self-help groups are not only beneficial to the individual, but also important for community development and citizen activism [2000, 332-3]. Similarly, Offer notes the importance of individuals feeling listened to, rather than just talked at, as well as the emphasis among users of such groups on 'embodied' rather than 'learnt' knowledge [1999]. As Damen et al. note, self-help organisations have been associated in the literature:

with the challenge to the authority of professionals of experiential knowledge [2000, 332].

Jack and several other writers [Croft and Beresford: 1995; Gibson: 1995; Anderson: 1996] have argued that self-help is the model of services most likely to further the empowerment of users, associating self-help with the idea of control. In Jack's view, power cannot be given, only taken, and that therefore, professionals cannot empower service users, only enable them [1995, 16]. He goes further than writers such as Barnes and Walker above, criticising notions of 'consumerism' and 'participation' as insufficient to empower users of services [1995, 18]. The notion that professionals can help users to empower themselves is also dismissed by him [1995, 25-6].

As noted, one of the Edinburgh agencies was a self-help group, formed by some of the users of a social space agency, which had been forced to make all of its workers redundant after funding cuts. This agency was popular with several respondents. Some of these respondents had vague ideas about the ideological significance of 'self-help' while others were deeply involved in the organisation of this group, and referred to ideas associated with empowerment to explain this.

Asked what the idea of self-help meant to them, some respondents merely emphasised the support drawn from being able to be with and talk to other HIV-positive people. R8, for example, liked self-help organisations because:

you can just sit and talk to one another.

R7 was not entirely sure what self-help meant but appreciated the interaction with other people with HIV infection. She approved of the fact that the users had taken over the running of this organisation, although made this point in fairly vague terms, without suggesting that she might also want to become involved.

For other respondents, however, the most important point about this agency was the fact that it was now run by and for HIV-positive people, excluding workers. R2 explained her enthusiasm for this agency in the following terms:

there's always someone there to speak to you and it's positive people. It's no somebody saying oh ah [...] who doesnae ken because they've never experienced it themselves [...] If someone's talking to you, and they think that they ken everything, and they're not infected at all, and they've nae even got anybody in their family who's infected with the virus [...] it's like 'how do youse ken? You only ken what you are reading. You dinnae really ken what the feelings are like'.

While her explanation does not automatically rule out HIV-negative workers, her comments were made in the context of her deep involvement in the new self-help group. It is interesting to note the contrast between these comments and her strong attachment to her consultant and compliance with conventional medical strategies, mentioned in the previous chapter. It seemed that her belief in the value of

professional training in the medical context did not extend to matters of social care [also see Blaxter and Paterson: 1982; Cornwell: 1984].

Similarly, R6 emphasised the importance of peer support, pointing to the ‘incompetence’ of the former workers:

[the agency’s] getting better but that’s because there’s a lot of positive people involved in it. [...] it’s been total disorganisation and I don’t know why people can get paid for it, £18000 a year, the three workers.

Other respondents’ suspicion of professional training in the context of medical treatment was also reflected in their attitudes to social agencies. R9 preferred the self-help agency she had helped create, criticising the ‘patronising’ attitudes of volunteers in her home area:

a lot of people have a disempowering effect on us and [...] I like to do my own thing and support myself as long as I can.

R3’s explanation of her preference for a worker-less self-help agency indicated a strong association between her sense of control and independence, reflected in her personal definition of self-help:

I’m able and capable of doing it myself.

She was reluctant to present herself as a ‘service user’, and continued:

as far as the HIV services go [...] I’m an Aquarian [...] and we’re all very independent, and we all depend on each other rather than going to [...] [services].

R3’s notion of maintaining control contained a strong element of anti-authoritarianism. She commented that she was uneasy in the hierarchical, worker-led environment of one Edinburgh social space agency, at which the workers’ offices doors were locked, indicating, in her view, that the users were not trusted. She insisted that her knowledge and experience of HIV infection should be considered greater than that of any trained worker or professional:

at the end of the day I think that I'm better trained than the people who are actually paid in these places ...they're on £20000 a year, it's a lot of money [...] but I've got the same qualifications as the people who are sitting there making 20 grand.

The enthusiasm of several respondents for self-help groups was therefore high at the time of the interviews. These women characterised the presence of workers as a denial of their own knowledge about their condition, and capacity to make decisions for themselves. At the same time, their involvement in such organisations developed this confidence in their own abilities, reinforcing the importance to their identities of maintaining control. With respect to some of these women whose children were older and had now reached adulthood, this involvement might also be characterised as a substitute focus of identity to being a mother.

The Difficulty of Combining Long-Term User Involvement With Maintaining a Sense of Control Over Physical and Emotional Health

Several writers highlight difficulties associated with the self-help model. Hughes, writing as both the mother of a severely physically disabled child and professional social worker, did not doubt her need for some professional help, and criticises the more confirmed advocates of self-help for denying this [1995, 307]. Barnes and Walker make similar points with respect to the potential over-reliance on service user involvement. In their view, the majority of people

who seek to use health and social care services [do so] because they have needs which cannot be met from within their own personal resources. They are seeking to benefit from knowledge and expertise which professional training should confer [1998, 204]

They suggest that paid workers should seek out the quiet voices within agencies, pointing out that the majority of service users do not:

seek to commit substantial personal time and resources to engaging with the detail of administrative and managerial processes [1998, 204]

In her study of the members of the United Kingdom National Long-term [HIV] Survivors Group, Crossley suggests that such groups:

bear an important ambiguity insofar as they may actually encourage a greater 'disease-identity' dependency than would have been the case if traditional medical approaches had been utilised [1998, 525].

Crossley's findings recall similar comments already discussed in this chapter with respect to controlling the space occupied in the respondents' thoughts by HIV infection and its potential implications. Such comments include those made by R11 with respect to her withdrawal from a management committee.

Similarly, Cain and Roy point to another disadvantage for HIV-positive people of too great a level of involvement in service provision: the direct effect on their health. As discussed in the previous chapter, a very important element of the respondents' notion of control was the desire to protect their physical health. This aim may be compromised by over-involvement:

Maintaining one's physical, mental, emotional and spiritual health is a full-time job for many people living with HIV/AIDS [...] AIDS organisations can be very demanding workplaces [...] Some HIV-positive respondents noted that the effects of long hours and a stressful work environment are a concern. One man stated 'I think it may be, quite frankly, doing more harm than good' [2001, 428].

They also note the potential difficulties for the organisation itself should people become ill.

Several respondents referred to similar difficulties in this study. R11's comments were based on her previous experience:

self-help support groups, they're fine, they're brilliant but you need someone there to say right, to take some of the stress and do the actual nitty gritty.

She was concerned about the respondents involved in the Edinburgh agency:

they're all positive, they're all knackered themselves out you know, doing too many stints and what not.

Despite her great enthusiasm for her self-help group, R3 was coming to similar conclusions by the time of the second interview:

I've been there everyday since I last seen you [...] I've learnt loads, I had to be the administrator there, [as there's] no workers there now, I've had to deal with every single solitary thing. It's been really hard [...] the two of us are knackered [...] I want two months off [...] this cannot be healthy for me.

Another respondent also referred to arguments between the respondents involved. R3's experience provides another potential example of fluctuation in a respondent's views of the compatibility of service involvement with her sense of control. In this case, service use, associated by the respondent with empowerment, was beginning to conflict with another important concern relating to control: the need to protect emotional and physical health.

Conclusion

This chapter has traced the relationship between the respondents' concern for control and the respondents' use of HIV-specific voluntary social service agencies, providing further confirmation that an exploration of users' identities, and of the consequent emotional significance of service use, is important to enhancing our understanding of service use.

The respondents' use of social services may be better understood in the context of their need to negotiate with several powerful professions and bureaucracies in order to maintain control over their everyday needs. It is, therefore, unsurprising that respondents were particularly appreciative of services that enhanced their sense of control over these resources, and particularly of services providing assistance with negotiating the complexity of the social security system. It is, however, of concern, that the availability of such services seemed to be undermined, at the time of the interviews, by lack of funding. It is also noteworthy that few services provided the respondents with help to negotiate another basic resource, of great importance to their post-diagnosis identity, namely their housing.

This chapter has also illustrated, however, that the link between the respondents' sense of control and their use of 'social space' agencies is complex, and that the importance to the respondents of preserving a sense of control does not imply any specific degree of use. The respondents had different ideas as to the compatibility of

social space agencies with their sense of control. On the one hand, some respondents found it more difficult to reconcile the use of these services with their concern to limit the space occupied by HIV infection, and its potential implications, in their thoughts. For others, the use of these services was an important means of protecting their emotional health. Although this perception might vary over time, these respondents drew strength from being able to discuss their experiences and problems with people who shared them.

Another element of the respondents' sense of control related to the possibility for user involvement in the services, in terms of their relationships with individual workers, as well as participation in policy-making. Nearly all the respondents emphasised the importance of trust to the continuity of their relationships with workers, criticising those workers who did not respect their views. Several respondents were also concerned to be involved with the policy-making processes of the agencies they used. Often, however, their experiences of being minority or token HIV-positive members of management committees detracted from their sense of control rather than enhancing it. This experience had led some respondents, who tended to emphasise the importance of 'embodied' as opposed to learnt knowledge, to advocate for self-help agencies with little or no involvement of professional workers. For this minority of respondents, their sense of control had become tied to being able to influence the direction taken by the agencies with which they were involved. For some, this element of their sense of control seemed to have been elevated to the level of a career option, perhaps as a replacement for the commitment involved in surviving until their children reached the age of sixteen.

The difficulty of trying to maintain control in all of these inter-related areas was also evident. The respondents' concerns to protect emotional and physical health, on the one hand, had to be balanced with the importance of obtaining a degree of influence over the decision-making processes of agencies with which they were involved, on the other. Several respondents provided examples of how they had withdrawn from involvement in management committees and work with self-help agencies when one activity had come to dominate the former. The respondents' concern to protect their sense of control may be understood as a delicate balancing act between all of the

elements of post-diagnosis identity discussed in this thesis. The implications of these findings for service providers will be discussed in my conclusion.

Conclusion

This project developed in response to several gaps which I perceived in the literature in 1995. In particular, little attention had been paid to the experience of HIV-positive women or to social care for people with HIV infection. I was also concerned by the 'matter-of-fact' tone of much of the available literature on HIV social service use, which seemed to imply that once a need had been identified, a relevant service provided, and all practical, including informational, barriers to its use countered, it would be used. Inspired by a concern to examine whether or not service use might be a more complex issue than this, I decided that a contextualised exploration of HIV-positive mothers' social service use would be a useful contribution to the literature.

Conclusions as to Methods

In the light of the lack of literature in this area, an exploratory study of the meanings and processes underlying HIV-positive mothers' service use, employing semi-structured interviews, seemed appropriate. I decided to employ a case study approach in a service rich location of relatively high HIV prevalence. My aim was to examine the context surrounding the use and non-use of services in a location where the availability of services was not a major issue.

Thinking about the strengths and weaknesses of the methods used, in the light of my aims, I came to the following conclusions. My use of two interviews with each respondent did advance my rapport with them, as hoped, as well as overcoming some of the problems inherent in retrospective accounts. Moreover, the introduction of a temporal aspect to the research was successful in reflecting the unpredictability of living with a chronic illness interspersed with acute episodes. Some respondents described themselves as generally well or as generally ill at the time of both interviews. This method was also able to capture the experience of other respondents whose mental and physical condition changed radically in the relatively short period between their interviews, with profound consequences for various other aspects of their lives. Similarly, the use of two interviews also reflected changes in the

respondents' relationships with family members and others between the two interviews, illustrating how service use was often embedded in these relationships.

The use of two interviews also allowed for a dynamic relationship between data and methods. My aims with respect to the second interview evolved over the course of the project, as a result of the intermediate analysis I undertook after the first interviews. I then used the second interviews to further explore various recurrent first interview themes. I also provided each second interview respondent with a copy of a time-line reflecting the chronology of their service use as compared with other major events in their lives. In some interviews, this formed the basis for long discussions, prompting less structured exchanges between interviewer and interviewee than is often the case, even where a semi-structured topic guide is used.

In contrast, however, my suggestion that the respondents complete diaries of their service use between interviews was entirely misguided, in spite of recommendations to the contrary in the literature. For most of these working class women, the written word was not a comfortable or much-used means of communication. Several respondents indicated that they had forgotten why I had given them notebooks. Given that I had provided a reminder of the books' purpose on the inside cover, such comments may have covered some degree of embarrassment on their part.

Contribution to the Literature on Living With a Chronic Illness

This research focuses on post-diagnosis social service use as an important aspect of living with a chronic illness such as HIV infection. As such, it extends the literature on living with a chronic illness to an important, but neglected, area. This research also adds to this literature in other ways as will be discussed in this section.

My interpretation of the interviews was greatly influenced by the approach underlying Bury's notion of biographical disruption [1982, 1991]. In his seminal 1982 article, he described the effect of chronic illness in the following terms:

First, there is the disruption of taken-for-granted assumptions and behaviours [...].
Second [...] a fundamental re-thinking of the person's biography and self-image

[...]. Third there is the response to disruption involving the mobilisation of resources in facing an altered situation [169].

The first branch of this notion of disruption fitted well with the respondents' accounts of brutal communication of their diagnosis, the stigma attached to HIV infection particularly in the 1980s, their own feelings of contamination, and their overwhelming fear at receiving what was then a terminal diagnosis. As Bury put it, diagnosis:

marked a biographical shift from a perceived normal trajectory through relatively predictable chronological steps, to one fundamentally abnormal and inwardly damaging [1982, 171].

Although these women had suffered from many of the same problems as those recounted by Ciambrone [2001], often including domestic violence, addiction and poverty, the rawness of their accounts suggested that the disruption caused by this diagnosis was intense.

Bury's article also identified a subsequent engagement in biographical work, reconstructing and maintaining a sense of personal integrity in spite of this disruption. He further analysed the sub-tasks involved in this 'work' as those of maintaining perceived control, maintaining a positive self-concept and maintaining a sense of normality as elements of this process [1982, 169-70]. These elements of Bury's conception of chronic illness were also well reflected in the data.

In particular, the respondents in this study emphasised that they had tried to continue as normally as possible post-diagnosis [also see Pierret: 1997]. 'Normality' seemed to provide them with a source of respectability with which to counter the stigma of their diagnosis. For several respondents, a narrative of 'normality' also contained an element of transformation underlining how they had changed their lives since overcoming addictions to opiates.

Bury also identifies the potential for subtle differences of shifts in the meaning of normality:

normalisation [...] may refer to the psychological 'bracketing off' of the impact of the illness, so that its effects on the person's identity remain relatively slight. On the other hand 'normalisation' may also mean treating the illness, or treatment regimes as 'normal', and incorporating it more fully into the person's identity [460-1].

In this study, this distinction tended to reflect a development over the years from the former meaning of normality towards the latter. This was particularly well reflected in the respondents' service use, an issue under-developed in the literature. Initially, and in the early years post-diagnosis, most respondents fought to maintain a self-perception which did not include HIV infection. Although most respondents attended hospital periodically for check-ups at this time, social service use seemed to be incompatible with this conception of continuing as normal. A particular problem was that the use of HIV-specific social services was often perceived by the respondents to symbolise the progression of the virus, and, therefore, the loss of 'normality'. These barriers to social service use often endured for some years, even as respondents shifted towards a narrative of living normally in spite of their diagnosis.

Over time, however, several respondents re-negotiated the meanings of certain services, on an individual and piecemeal basis, allowing the use of specific social services while still maintaining an overall narrative of living 'normally'. In some areas of their lives, some respondents came to incorporate HIV infection, and service use, into their identity to a much greater extent, extolling the transformation in their lives brought out by involvement in 'social space' agencies. The use of social space agencies provided these respondents with a safe place in which to discuss common problems and to reinforce a feeling of being normal in spite of their diagnosis.

Another important element of the respondents' emphasis on living their lives normally was the importance of being considered 'normal' and, therefore, good, mothers. This concern also reflected another element of Bury's post-diagnosis biographical work: the need to maintain a positive self-concept. Most respondents emphasised the strategies they had employed to try to ensure that their children's childhood was as normal as possible in spite of their diagnosis. Once again, this

crucial element of the respondents' post-diagnosis identity was particularly well illustrated by the respondents' use of children's services. The use of those statutory services considered to be 'normal', such as medical services and the school system, raised few concerns in this regard. In contrast, any involvement with the SWD was perceived to undermine the respondents' identities as normal and good mothers.

For one group of respondents, most of whom were diagnosed relatively early in the Edinburgh epidemic, very little service use was regarded as compatible with providing a normal childhood for their children. In contrast, for several respondents, most of whom were diagnosed more recently, social service use was considered generally compatible with this aim. For these respondents, the use of a residential respite facility, foster carers or buddies could help to ensure that their children participated in normal childhood activities. Further, they had come to the conclusion that specialised playgroups, at which HIV infection was discussed, did not make their children different, but provided them with a space in which they could feel the same as everyone else.

Over time, another important element of continuing as normal in spite of the diagnosis related to what Bury might describe as the respondents' mobilisation of relational resources [1982, 175]. In this study, the respondents' preference was for informal care, provided by family members or friends. Some of the respondents could also draw on support from networks of other HIV-positive members of their families. Informal care was seen as compatible with their identities as independent people living normally in spite of their diagnoses.

The 'normality' of these relationships related in part to the values expected to underlie such long-existing informal relationships. These included a shared biography, love, duty, trust and reciprocity. In this study, the interviews revealed that the respondents also appreciated these values, however, in the relationships they developed subsequent to diagnosis with other service users and with service providers. Several respondents enthused about their often long-term relationships with consultants or GPs, highlighting 'informal' aspects of these relationships such as reciprocal trust and sometimes shared biography. In fact, some respondents

referred to medical professionals as ‘friends’, while others described workers from a children’s counselling services as ‘family’ members.

Bury’s conception of the ‘sub-tasks’ involved in biographical work also includes the need to ‘maintain perceived control’ [1982: 169]. The content of this concern is not made explicit in this article, but does seem to include several issues discussed in this thesis with respect to the respondents’ concern to maintain control over their post-diagnosis identity.

Bury points to the importance to his respondents of taking care of their physical health. In this research, this is also an important element of control. The strategies employed by the respondents to maintain their mental and physical health were also overlain for some by moral concerns in the manner described by Crawford [1994] and Crossley [1998]. Once again, therefore, there seemed to be a strong relationship between elements of the biographical work undertaken post-diagnosis and maintaining a reputable post-diagnosis identity.

Bury also examines medical treatments and relationships with medical professionals and the need to negotiate with medical professionals over treatment:

Negotiating over the appropriate use and effects of treatment regimens as well as the significance of symptoms enhances adaptation to a disrupted biography, or at least achieving a measure of stability [1991, 460].

In this study, one element of the respondents’ concern to maintain control related to treatment regimes and the medical decision-making process. While none of the respondents had entirely rejected the resource of medical expertise, some respondents took this concern further, challenging the ‘learnt’ knowledge of their consultants with their own ‘embodied’ knowledge. Similar concerns influenced these respondents’ preference for a self-help environment, excluding paid workers. These respondents were in a minority, but the social service use of all the respondents was influenced by whether or not they perceived that a particular service would enhance, or detract from their sense of control.

In his 1991 article, Bury points to the importance of the social context in which chronic illness is experienced. In this study, this aspect of the respondents' concern to maintain control receives more emphasis. The fragility of their financial and material circumstances was a major concern to the respondents, all of whom depended on state benefits for their income, and none of whom owned the property in which she lived.

Maintaining income levels was also closely associated for these respondents with the other elements of control discussed above, for example their ability to implement strategies to protect their health. Overall, keeping control involved maintaining a fragile balance between several disparate areas of their lives, all of which were perceived to be inter-related.

In conclusion, therefore, Bury's conception of chronic illness as a biographical disruption provided a powerful tool for the analysis of these interviews. In particular, the notion of biographical work, involving the mobilisation of various 'resources' to respond to the diagnosis, was useful in examining the long-term process of identity construction engaged in by the respondents over the years since their diagnosis.

Bury does not emphasise the notion of 'identity' a concept employed, for example, by Charmaz [1983]. To my mind, however, the idea of identity is implicit in the idea of 'biographical work', and provides a tool for analysing which and how 'resources' are employed, as well as the inter-relationships between the different elements of 'biographical work'. Bury recognises that medical expertise is a resource on which service users may draw, but does not extend his analysis to social service use. This research has tried to fill this gap. In doing so, I have highlighted several elements of post-diagnosis identity, less emphasised in Bury's work. For example, I pointed to the importance of financial and material context and of the inter-relationship of several disparate concerns in trying to maintain a sense of control. In particular, I highlighted the importance to the respondents' post-diagnosis identity of motherhood. The wider significance of these findings for the literature on women, in general, and as mothers, will be discussed in the following section.

Chronic Illness, Relationships and Motherhood on a Low Income

Motherhood was crucial to the respondents' post-diagnosis reconstruction of identity, far outweighing the significance of other potential sources of identity, such as partnership or work. This was evident in the importance to most respondents of surviving until their youngest child reached the age of 16. The depth of this concern was further illustrated by some respondents' disorientation, even concern that they might die, once this aim had been accomplished.

In some respects, this emphasis on motherhood recalls Carricaburu and Pierret's notion of 'biographical reinforcement' [1995]. They emphasise that one of the resources on which some HIV-positive men may be able to draw in their post-diagnosis 'biographical work' may be the collective group history of haemophiliacs and homosexuals. Motherhood does not, however, offer a collective identity in the same way. Furthermore, several respondents' emphasis on good motherhood served less to reinforce a pre-existing element of their identity than to construct a reputable identity by emphasising both the distance they had put between themselves and their drug-using past, and the effort they had invested in doing so.

Bury's 1982 article is based on interviews with respondents newly diagnosed with rheumatoid arthritis. The majority of these respondents were mothers, many with young children, but their experience of chronic illness was not interpreted in this light. Instead, Bury focuses on the physical effects of illness, for example, on their ability to work. On reflection, Bury's lack of interest in these women as mothers is puzzling. Since several other authors in this field also do not discuss this issue, this finding may suggest the need for a greater focus on gender and motherhood in the literature on chronic illness. I used literature on motherhood [Oakley: 1979; Boulton: 1983; Silva: 1996] to further explore the significance of this source of identity to the respondents, as well as their potential difficulties in asserting it.

More generally, the degree to which these respondents understood their lives, and even their continued existence, in terms of motherhood is striking. These

respondents' sense of being a moral person seemed to be exclusively tied to being good mothers.

Other important findings related to the nature and quality of these working class women's relationships with male partners. In the context of their illness, it was clear that the respondents' preference was for informal support from family and friends. Many respondents did receive a high degree of support from this source. With some exceptions, the great majority of this support came from female relatives. In contrast, the lack of support from the respondents' male partners was striking. Other research has highlighted the caring role played by the husbands of older women [Arber and Gilbert: 1993]. These findings are not echoed in the respondents' accounts, however. In many cases, ideas of 'partnership' or 'intimacy' seemed highly inappropriate for the relationships described. Even in the few cases where partners provided practical help, they did not support the respondents emotionally. This lack of support contrasted sharply with the respondents' accounts of their own experience of caring for male partners or relatives who had died of AIDS.

At the same time, the respondents' lack of comment or anger as to the asymmetry in these relationships suggested that they had very low expectations of their male partners. Notions dear to romantic literature and some women's magazines, such as the search for a 'life partner' or a 'soulmate' seemed entirely absent. Instead, perhaps influenced by previous experiences including domestic violence, the main concern of many respondents was to limit the control of prospective partners over their living arrangements by rejecting the idea of co-habitation.

The respondents' low expectations as to income are also noteworthy. Their accounts suggested a feeling of perceived wealth, and in some cases, disbelief that Disability Living Allowance [DLA] had made such a difference to their lives. Even allowing for the fact that DLA had often doubled their income, that they were not liable to pay tax and most, if not all, of their rent would be covered by Housing Benefit, their annual incomes fell a long way short of the average salary. To this extent, the respondents' accounts accord with Ciambrone's argument that the disruption caused by an HIV-positive diagnosis may be more severe for the relatively privileged than those with lower incomes. These respondents' main point of comparison were basic

levels of Income Support, and, ironically, several respondents' income had increased substantially since diagnosis.

Further, in contrast to research findings [Payne: 1991, Sobo: 1995] on poor women's perception of the greater reliability of the state in providing income as compared with men, this may not be the case where levels of benefit, above the basic means-tested rates, are involved. These interviews reflected a high degree of anxiety with respect to the fragility of their entitlement to DLA and the potential loss of a resource which helped them to better protect their health and provide for their children's future. This fear was underpinned by previous experience of living on basic rates of Income Support, supplemented by odd jobs on the side.

Suggestions for Future Research

The findings of this study suggest many fruitful avenues for future research. Some of these are implied in the focus chosen for this research referred to in the above discussion. In particular, this research has pointed to the advantages of exploring chronic illness and service use within a broad social context and from the perspective of potential and actual service users themselves. Similarly, while the literature on HIV services has much to learn from the literature on chronic illness, in my opinion, the literature on chronic illness should pay greater attention to service use as embedded within and contributing to the experience of chronic illness.

The findings of this research also suggest the interest in pursuing similar studies both in Edinburgh, and in other locations with different populations. My research was completed in the 1990s. At that time, several respondents commented that the stigma attached to an HIV-positive diagnosis was less than in the mid-1980s. Medical treatments have also moved on substantially since the 1990s. As such, it would be interesting, in methodological and substantive terms, to repeat this research [see Pierret: 2001].

It would also be useful to explore actual or potential service users' perceptions of service use in other rural and urban locations with a lower prevalence of HIV infection and where attitudes towards HIV infection may differ substantially. This

study has focused on the accounts of women who are mothers and their post-diagnosis identity, including their changing conceptions of normality. Examining the service use of women who are not mothers in the light of their conceptions of normality might provide an interesting contrast. Similarly, an exploration of the experience of older women would provide a greater insight into life stage effects. As undertaken by Aldridge and Becker in their work on child carers [1993, 1994], parallel studies of the perspectives of children, to add to those of parents would provide further insights. Focusing on children affected by HIV would be a welcome addition to the literature, which, with some exceptions [Cree et al.: 2002] has focused on children with HIV infection.

Another interesting avenue of research might be to explore actual and potential service users' understandings of the different sources of help available to them. The transcripts revealed that the respondents' caring relationships often breached the institutional boundaries between informal support and more formal services. For example, some of the respondents' strongest informal supports developed from relationships nurtured through service use. Some of these informal support arrangements also developed into more formal self-help groups. Looking at sources of help from the respondents' perspective also suggested that informal support should not be conceptualised only in terms of existing relationships, since several of these relationships developed subsequent to diagnosis. The interviews therefore suggested that the respondents' perception and experience of different types of care was more complex than allowed for in much of the literature.

Further, analysis of the nature and quality of the caring relationships most appreciated by the respondents suggested the importance of reciprocity in these relationships, not only with informal supporters, but also with professionals and other workers. Some research has criticised the conceptualisation of caring as a dyadic relationship in which one person cares while the other is cared for, and is, therefore, dependent [Morris: 1998]. The nature of HIV infection, with periods of relative 'wellness' suggests that diagnosis need not lead to the disruption of all reciprocity as Bury implies [1982, 180]. Further research into the nature of this

reciprocity and the forms which it may take in relationships with service providers, and into the perspective of service providers on this issue, would also be of interest.

Another fruitful subject of research might relate to the potential health benefits of long-term relationships between service users and providers. The respondents' emphasis on the importance of thinking about their diagnosis in certain ways and not others, also suggests the potential significance of research into the relationship between such narratives, including the importance of surviving until a child attains the age of 16, and health. Some commentators, including Crossley [1998], point to the danger of placing too much emphasis, for example, on 'positive thinking' and blaming those too weak to adopt this strategy. In her view, over emphasis on the protection afforded by 'positive thinking' might lead to destructive self-blaming, should adherents of these strategies themselves become ill. On the other hand, in this study, R1's experience suggested that a self-image in which 'nothing is normal' might not only reflect depression, but feed into it.

Recommendations for Practitioners

In an exploratory study such as this, which has not focused on the evaluation of services, it may seem presumptuous, to make detailed recommendations to service planners and providers. The findings of this study do, however, suggest some points which may be of interest to social service planners and providers.

Post-diagnosis Identity Reconstruction and Service Provision

It would seem important for practitioners to take account of the meanings and understandings and context of their clients, and potential clients' service use when planning, publicising and providing services. For example, considering how to assist service users with their individual process of normalisation of service use by emphasising how service use can help them to live a normal life, might facilitate clients' service use and form the basis for a better service user-provider relationship. Publicity pointing out how particular services could help users to get on with a normal life might also help to break down some potential service users' resistance to service use. In other words, it may be possible for service providers to assist service users with the process of integrating service use into their post-diagnosis identities.

This point is also illustrated by the significance of motherhood to the respondents' post-diagnosis identities. In the light of several service providers' concerns that HIV-positive mothers were not using their services, the potential for service use to support the respondents' identities as good mothers providing a normal childhood for their children is important. In contrast, several service providers I interviewed seemed to accept the idea, current among the 'early-diagnosed' respondents, that service use was not normal, and could not be normalised. Changing these conceptions of service provision might also influence future decision-making on advertising and organising services, making them more attractive to potential service users who are also mothers.

The Respondents' Preference for Informal Support and Service Provision

The respondents' emphasis on the importance of informal support has several implications, for example for service providers' own relationships with clients and for the design of social space agencies.

The existence of several networks of HIV-positive family members suggests the need for service providers to consider other sources from which service users might be accessing information, or to which service users might be passing information. The existence of these networks emerged unexpectedly from the transcripts, but reflected the pattern of transmission of the Edinburgh HIV epidemic. Similar networks might also exist, therefore, among people with Hepatitis C, for example. As such, if any important differences in information are relevant to different genders, for example, this might be addressed in agency literature, and potentially, in their dealings with individual clients.

My findings with respect to the importance of the nature, formality, intensity and reciprocity of caring relationships have several implications. They suggest that service providers should not under-estimate the importance of less formal elements of their relationships with service users, particularly, where, as with many chronic illnesses, these relationships may last for some time. There may well be dangers for professionals of becoming very emotionally involved with a large number of clients. At the risk of sounding patronising, however, it seemed that professionals should not

under-estimate service users' appreciation of being treated with everyday niceties and personal touches. Over time, it also seemed important that such relationships involve a degree of mutual trust, or recognition of the knowledge that the service user might have developed in dealing with their condition.

The respondents' comments as to the advantages and disadvantages of informal support also have important implications for the physical design of those social services which provide meeting spaces. The interviews suggested the importance of providing social spaces in which the informal elements of relationships with other service users or workers may be nurtured. Individual respondents were comfortable with different levels of involvement with the HIV-positive people they had met since their diagnoses. While some respondents were happy to mix primarily with other HIV-positive people, others were concerned that such involvement would entail a heavy emotional burden.

These diverse preferences might be catered for by the provision of different types of social spaces. The wide popularity of one of the social spaces discussed in the interviews, however, indicated that some such spaces may be more versatile than others. The café provided by one of the Edinburgh agencies seemed to provide the respondents with a 'normal', readily understood format for a social space that could be used as intensively, or as fleetingly, as they desired. In this context, close relationships involving a high degree of reciprocal emotional support could develop and be continued within or outwith the agency. At the same time, this space could be used more intermittently by service users, who might prefer to keep these relationships to surface level, and to have the option of using its facilities without feeling they are letting anyone else down.

Implications for Service User Participation in Decision-Making Processes

The findings also suggest the importance of considering further opportunities for user participation in HIV social services. Although workers' jobs are often made more difficult by a lack of flexibility, the need to highlight the importance of listening to and understanding the priorities of services users was suggested by the interviews. They also suggested the need to review the methods employed to consult

users as to services provided, and to include them in agency policy-making processes. The methods employed by the Edinburgh agencies at the time of the interviews were not perceived by the respondents' to enhance their control over decision-making. With the exception of a few measures, for example, a liaison committee with hospital consultants and the idea of appointing a worker to better consult service users, the methods employed were generally perceived to detract from their sense of control.

Gaps in Service Provision

The transcripts also pointed to important gaps in service provision for mothers and children.

The need for consistent foster carers for children was recognised by a service provider I interviewed. She emphasised that more money should be spent on advertising for foster carers and on paying higher retainers to them to try to ensure that short-term respite was always with the same carers. This concern was also recognised by the National Foster Care Association [1997]. Similarly, a representative of the SWD I interviewed was concerned that structural boundaries in social work should not prevent foster carers from adopting the children of HIV-positive parents, or parents with other illnesses, in the event of their death. In this study, R11's story indicates that where a mother cannot rely on family to look after her children in the event of her death, such arrangements might provide both the parent and affected child with some reassurance in the face of undermining uncertainty.

The service providers I interviewed were less concerned, however, by the general lack of services for young people affected by HIV infection and aged over 16. This gap in service provision again reflects general structures of social work and other services whereby young people are generally required to be assessed for hard-pressed adult services. Several respondents and their children were, however, very concerned that their children, once they reached a certain age, would be excluded from groups in which they had developed strong supports and relationships. Excluding children in this way takes no account of their individual needs. Further,

for statutory services to treat young people as adults at the age of 16, is questionable in the light of their minimal access to social security benefits with which to support themselves at this age. The flaws in this age-determined approach to service provision were underlined in this study by the numbers of older children mentioned by respondents as being affected by their parents' diagnosis or death, who had never previously used services, but who they thought might now benefit from such support. In one case, a respondent's children had not learnt of their mother's diagnosis until their mid-teenage years. Other respondents' children had been long-term carers for their mothers and, it seemed, were finding it difficult to establish their own independence.

In the light of the importance to the respondents' sense of control of maintaining their financial and material circumstances, it is unsurprising that advice workers were greatly appreciated. As such, the characterisation of these services as 'non-frontline' appears misconceived. The importance of income to any individual's control over their lives, and to their sense of independence, is undeniable, but is not, it seems, always appreciated by funders of social care. Although some of the respondents' difficulties with the social housing bureaucracies related to the overall scarcity of public housing, similar points may be made both about the availability of, and publicity around, housing advice.

My interviews with both service providers and service users, also suggested the need for changes to the benefits and housing system's eligibility criteria. The effective abolition of life awards of DLA, in spite of the demise of the Benefits Integrity Project, means that people with HIV infection will be subject to the anxiety of continual reassessments. On several occasions, it was pointed out that DLA assessors give insufficient weight to the chronic fatigue, experienced by people with HIV infection, which makes their completion of everyday activities more difficult. The unpredictability of HIV infection further complicates their assessment for this benefit, as well as for medical points in respect of housing transfers. Such problems might be avoided if the degree to which a person's condition is likely to worsen in the long run, rather than in the short-term should be taken into account, to try to avoid the necessity for several moves as a person's condition worsens.

A Final Thought

In his 1991 article, Bury advocated for:

A multi-dimensional view of [chronic illness] and its impact on everyday life [463].

This research has attempted to do just that by emphasising the importance of social context and focusing particularly on the aspect of living with chronic illness that is social service use.

In this study, I have raised many difficulties with the respondents' use of social services and criticised some aspects of the services available. Overall, however, it was clear that many of the specialised social services available were much appreciated by the respondents, or had been at one stage since their diagnosis. The different types of services appreciated by the respondents also suggested the need to support a diversity of services. For such services to exist, adequate long-term funding is essential, not only in respect of HIV-specific services, but also mainstream services, such as housing. My interviews with HIV services providers revealed, however, that many organisations were then reluctant to publicise their activities as they did not have the resources to cope with an influx of new clients, let alone to develop new services.

Recent conversations with Edinburgh service providers have indicated that since these interviews were completed, funding for social services, including most of those referred to in this thesis, has decreased substantially. The impression is that health funding has been diverted from social services to support the huge cost of combination therapies. That these therapies have made a great difference to many HIV-positive people's lives is not disputed. The findings of this thesis indicate, however, that living with a chronic illness, particularly one that remains potentially life-threatening, raises many complex issues in addition to obtaining the necessary medication. That these social aspects are now receiving less attention is cause for considerable concern.

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Appendix 1

Initial Letter to Service Providers

Dear [Addressee]

I am a PhD student in the Department of Social Policy at Edinburgh University. I am writing to ask you to provide me with some help in connection with my thesis research project, the working title of which is *Additional Burdens?: Motherhood, Low Income and HIV and AIDS*. A major focus of this study is the provision of social services.

First, I would like to discuss social service provision for mothers with HIV or AIDS with you or another member of your organisation preferably in April or early May 1997. This discussion would provide a valuable contribution to the development of my research. This discussion would take about 60 minutes and cover the following topics:

- brief profile of the social circumstances of the mothers with HIV or AIDS in contact with your organisation;
- your experience of the needs for services of mothers with HIV or AIDS and their families and of how these needs evolve;
- your assessment of the factors which may encourage, discourage or prevent mothers with HIV or AIDS from contacting different social service organisations and how these factors may affect some women in particular;
- service provided by your organisation which are used by mothers with HIV or AIDS and their families;
- aims behind the services provided;
- any statutory responsibilities of your agency or department;

- routes of referral to your organisation and the agencies to which your organisation refers mothers with HIV and AIDS;
- any factors which may sometimes hinder the development of a good working relationship between service providers and mothers with HIV or AIDS;
- your views on the quality of service provision to mothers with HIV or AIDS in general;
- thoughts on the organisational structure of service provision for mothers with HIV or AIDS.

Second, I wonder if you might be able to help me to contact a small number of mothers who might take part in the study which aims to study social service provision primarily from the users' perspective. I would like to interview mothers receiving services from a variety of different organisations, starting in June 1997. I would like to be put into contact with women who have been diagnosed as having HIV or AIDS for varying lengths of time.

My departmental address and phone number is at the top of the letter. I can also be contacted by phone on [.....]. I will phone you in the next ten days to see if we can fix up a meeting to discuss my project. My research is being supervised by Dr. Fran Wasoff of the Department of Social Policy and Dr. Steve Platt of the Research Unit for Health and Behavioural Change. They can be contacted on [phone numbers] respectively, if you have any questions about the research.

Thank you for your assistance.

Yours sincerely,

Sarah Wilson

Appendix 2

Topics to be Discussed With Service Providers

Thank you very much for agreeing to be interviewed.

As you know, I am a PhD student at Edinburgh University. My research project focuses on mothers who have HIV or AIDS and how they cope with the management of their diagnosis in the context of their family responsibilities, living conditions, and contacts with service providers.

At present I am interviewing a number of service providers. As a result, I hope to gain an understanding of service providers' perceptions of the needs of mothers with HIV and AIDS with respect to the provision of social services, as well as a social profile of your clients.

One thing I would like to clarify before beginning the interview is your position with respect to confidentiality. I was planning to report the opinions of service providers by referring to their position in their organisation and to the organisation itself in some generic form eg. *(read prepared formula)*

Would this be acceptable?

(if not, what would you prefer?)

1) Details of the Respondent and His or Her Organisation

I would first like to ask a few questions about the organisation you work for and your particular job.

Name of Respondent:

Organisation:

Could you give me a job title and brief summary of your responsibilities? *(NB I need to clarify if a person is a practitioner).*

Is the organisation in the (a) statutory or (b) voluntary sector? *(Circle one)*

Could you tell me who funds this organisation?

For the next few questions, I would like you to think back over the last year.

Do you happen to know approximately how many mothers with HIV or AIDS were in contact with your organisation over this period?

Again thinking back over the last year, do you happen to know by what routes mothers with HIV or AIDS were referred to your organisation?

Wait for response and tick off and then prompt: For example were some of them:

self-referred	Y	N
GP	Y	N
by other agencies	Y	N

You mentioned some other agencies, could you tell me which agencies these were?

Do you know whether each of these routes is equally common?

Of the mothers who are self-referred, do you know how they find out about the organisation?

Tick off if mentioned: If not, ask about:

Recommendations (other users)	Y	N
Publicity	Y	N

Is the organisation involved in any outreach work in relation to women with HIV or AIDS?

If so, could you describe any of this outreach work that targets mothers with HIV or AIDS?

If you recommend other agencies to mothers with HIV or AIDS, could you tell me which agencies and why?

And you have/not mentioned some collaboration between voluntary and statutory services. In your opinion are there strong relationships between the 2 sectors dealing specifically with services for mothers with HIV or AIDS?

Do you have good relationships with (other) voluntary organisations eg. with self-help groups?

2) *Social Profile*

I'd now like to ask a few questions about your clients who are mothers with HIV or AIDS themselves. (This will help me to understand the social profile of your client group better).

I'd like you to think about mothers with HIV or AIDS who have been in contact with your organisation over the last year.

1) *Age*

Would it be possible for you to indicate the age breakdown of your clients who are mothers with HIV or AIDS?

19 or under:

20-29:

30-39:

40-49:

50+:

Thinking over the last year, do you know roughly what number of your clients who are mothers with HIV or AIDS are: *(if you can't give proportions, perhaps could you indicate which is the largest group)*

(a) HIV positive but asymptomatic

(b) HIV positive but have experienced some related illness

(d) have been diagnosed with AIDS.

Do you know whether in many cases, other members of the family were HIV positive?

I'd now like to ask you to think about several (perhaps the last 4 or 5) of your clients who are mothers with HIV or AIDS who have been in contact with your organisation over the last year. (*Or - depending on whether or not the interviewee has direct client contact*) I'd now like to ask you to think about the mothers with HIV or AIDS who have been in contact with your organisation over the last year.

Could you tell me something about these mothers' families and the level of family support systems available to them? (eg the support they might get from partners or from their extended families).

If the following issues are not mentioned: Picking up on some of the points you've made.

Do you know whether some of these mothers (with HIV or AIDS) had/ have partners?

Do you know if these mothers with HIV or AIDS receive/d much practical and emotional support eg. from other members of their immediate or extended families?

(*if so, could you explain what type of support?*)

Do you know if there is/was great variation in the extent of practical and social support available to these mothers with HIV or AIDS?

Thinking about the same group of mothers (with HIV or AIDS), could you give me some idea of their levels and sources of income?

Do you happen to know whether social security benefits were an important source of income for these mothers?

(If so, which benefits?)

Could you give me some indication of their [general] housing conditions?

In many cases has there been a change in level of income and housing conditions since diagnosis?

Finally still thinking of these mothers:

Were problems of drug use present in their families?

Have many of your clients experienced mental health problems prior to diagnosis?

Have these problems increased post diagnosis?

2) Needs:

In the next set of questions I'd like to ask you about the needs of mothers with HIV or AIDS? The research I've read has suggested that many mothers with HIV or AIDS experience substantial problems. Thinking about the mothers with HIV or AIDS you have seen in the last year, could you tell me what these problems were/are?

If not mentioned: Could you tell me of any major factors which differentiate between mothers with HIV or AIDS with respect to their needs? (*prompt* eg diagnosis; drug use problems in the family)

Do you think that the needs of mothers with HIV or AIDS are very different to those experienced by other mothers who do not have HIV or AIDS but also live with an illness, on a low income, perhaps in poor housing?

Do you think that stigma or perceived stigma is a factor?

3) *Service Provision*

I'd like to move on now to service provision in more detail.

Does the organisation you work for have any statutory responsibilities?

Could you give me a brief indication of the work your organisation does with mothers with HIV or AIDS?

Tick off:	respite provision	Y	N
	planning for children's future	Y	N
	services for carers	Y	N
	counselling	Y	N
	benefits advice	Y	N
	alterations to homes	Y	N
	information	Y	N

If counselling and/or planning for the children’s future are mentioned then ask what these entail: (ie Could you tell me what planning for the children’s future/ counselling entails).

Apart from the services themselves, do you think there are other benefits for mothers with HIV or AIDS of contacts with your organisation?

Ask about the following if they are not mentioned:

social contact with others	Y	N
reassurance	Y	N
emotional support	Y	N

Do you know of any practical problems for mothers with HIV or AIDS in trying to use your organisation?

If not mentioned: For example, do some clients have problems:

- accessing the services of your agency? eg lack of transport.	Y	N
- problems of time management eg problems of multiple appointments for different members of the family in different places?	Y	N

Do you think that some mothers may be reluctant to contact your organisation?

If so: Why do you think this?

prompt: is there a stigma attached to social services?

is it perceived as not 'normal' in some way?

Does your organisation do any child protection work?

(if not: do you think that mothers with HIV or AIDS are less reluctant come to you because you do not have any child protection responsibilities?)

(if representative of funders: I've read that in London some local authorities have entered into agreements with voluntary organisations to provide services to avoid this type of problem. Have such projects been discussed in Edinburgh?).

For workers involved with child protection work:

I would like you to think of several mothers with HIV or AIDS you have seen in the last year and describe any child protection issues that were raised?

Could you explain to me what type of options were open to you in these cases and which options you selected?

Do you think these options will change/ have changed as of April with the implementation of parts of the *Children (Scotland) Act 1995*?

Do you experience any conflict between your different roles as a social worker working for the welfare of mothers with HIV or AIDS and their families but also being concerned with issues of child protection?

(prompt: Do you think that mothers perceive this as a conflict?

Does this affect your relationship with mothers? *(If yes, how?)*

Then continue:

If your organisation was in contact with some of the mothers who have now been diagnosed with HIV or AIDS prior to their diagnosis, how would you say that this diagnosis has affected their needs?

In your organisation, to what extent are mothers with HIV or AIDS involved:

(a) in decision-making with respect to the services they receive?

(b) in policy-making with respect to the organisation's services?

Do you think that service provision to mothers with HIV or AIDS in Edinburgh needs improving and if so, could you suggest ways in which service provision to mothers with HIV or AIDS could be improved?

Briefly, before moving on to some practical matters, I'd like to ask whether you found this interview frustrating eg were there some issues that you see as crucial that I did not ask you about?

Finally:

Thank you very much for answering my questions today as service provider. This will be a great help to me. Finally, I'd like to discuss a couple of further ways in which you could help.

First, if you have any records about the social characteristics or economic circumstances of your clients (eg the age and income), over the past year or few years, would it be possible for me to see them, in an anonymised form, and record the information?

Second, as you know, it is central to the success of my project that I can get speak to mothers with HIV or AIDS? Would you be able to help me with this? For example, would your organisation be prepared to help me contact some mothers with HIV or AIDS who are current service users or who have used your services in the past?

If not: would you be prepared to accept an opt-in strategy whereby I would provide you with letters and you could distribute them to mothers with HIV or AIDS who could then contact me?

Appendix 3

First Topic Guide For Mothers

Thank you very much for agreeing to be interviewed.

As you may know I'm doing a PhD at Edinburgh University on HIV-positive mothers, their experience of living with HIV infection, and their use of services. I'm focusing on these issues as I don't think that enough is known about the particular experiences, needs and opinions of HIV positive women. For example, I would like to find out how well you think social services fit into your everyday life, and how well they meet your needs.

Before starting the interview, I'd like to talk a bit about confidentiality. First of all, I won't write your real name in my notes. Nothing I write will allow people who don't know you to figure out your identity.

Throughout the interview, please remember that there are no right or wrong answers and you can stop at any time. Also, if there are any questions that you don't want to answer, then just tell me. Or if you want me to explain why I'm asking a particular question then just ask.

As you can see, I have a tape-recorder so I can concentrate more on what you are saying rather than taking notes. Do you mind if I use it? If you want me to turn it off at any point during the interview then just tell me.

Would you mind signing this consent form?

Do you have any other questions before we start?

(For my own use)

Date:

Place of Interview:

Organisation through which respondent contacted:

Name to be identified by:

Time taken: Start: Finish:

My comments/ observations after the interview:

(A) *Personal Details*

1) First, I'd like to ask a few questions about you

Are you from Edinburgh? (If so: From which area of the city?):

(If not: how long have you lived in Edinburgh? When did you come here?)

2) How old are you?

3) Do you have a partner? Y N

 Are you married? Y N

4) How is your health at the moment?

As you know the reason why I was put in contact with you is that I am doing research into the experience of social services of mothers with HIV or AIDS.

(b) Can I just confirm that you have been diagnosed as HIV-positive? Y N

(B) Income and Housing

5) Can I now ask you about the money you have to live on? Where does it mostly come from?

(These are for me to tick off. If benefit is the response I can ask which or for an amount which would indicate which)

own job		Y	N
own job plus FC		Y	N
another's job		Y	N
benefits	IS	Y	N
	ICB	Y	N
	DLA (rate?)	Y	N
	HB	Y	N
illegal income		Y	N

(b) Has the source of your income changed since your diagnosis as HIV-positive?

(c)(if relevant), how have you found dealing with the DSS/ brew?

(prompts)

(d) Have you ever been refused any benefits? Y N

(e) (if so) Have you made any appeals? Y N

(if so) How did you find that process?

(f) Have you had any help dealing with your benefits applications or any appeals? Y N

(if so), who from?

Were they helpful?

(6) Who owns the housing you live in?

(This list is for me to tick off)

SATA	Y	N
LA/ 'Council'	Y	N
HA	Y	N
Other		

(b) Have you moved since your diagnosis as HIV positive? Y N

Could you tell me why?

(c) Are you happy with your present housing? Y N

Why/ not?

(d) Have you had any problems with your rent (eg rent arrears)?

(e) Have you ever asked anyone for advice about your housing?

Who was this?

(C) Social Network and Social Support:

I'd now like to ask some questions about the people you live with and the people who are important to you (or who you see most frequently?)

(7) Can you tell me a bit about the people you live with? (eg children, partner, relatives, friends).

(b) Have the people you live with changed over the last two or three years?

(8) I'm now going to give you a piece of paper. Can you write on it, in anyway you want, the names of the people who are important to you. They can be anyone: friends, relatives, teachers, social workers, anyone who is important to you. (*leave time*)

(b) Now can you write under their names, whether they are a friend, relative, doctor, teacher, social worker etc (*may have done this already*) and how often you see them (eg daily, weekly, monthly, more rarely) (*leave time*)

9(a) Looking at your sheet, I'd now like to ask you to take this black pen and use it to circle those people on the paper who know that you are HIV-positive.

(b) Could you now take this green pen and circle those people you know to be HIV-positive.

(c) Now taking this red pen, could you circle the people you have got to know since you were diagnosed as HIV-positive.

(d) Looking at your sheet/picture, do you think it/this picture would be different if you had drawn it before your diagnosis? Y N

(If so) Can you tell me something about the differences?

(10)(a) When did you first know that you were HIV positive?

(b) How did you hear about it?

c) In general, have things changed for you since your diagnosis? Y N

(If so) Can you give me some examples?

(d) *(prompts)* Has your personal life been affected by having HIV?

(e) Has it affected your sexual relationships?

(11) What would you say has *not* changed since your diagnosis?

(12) And how do you see your life in 2 or 3 years time?

(prompt) What are your plans for the future?

(13) I'd now like to ask you about any help you get eg with the housework, with the children?

Does anyone help you with the housework? Y N who? how often?

Does anyone help you with the shopping? Y N who? how often?

Does anyone look after the children sometimes? Y N who? how often?

Do you have someone to talk to when you need to? Y N who? how often?

(c) Do you help out other people (in similar ways?)

(d) Do you find it difficult to ask for help?

(if yes) Can you tell me why?

(D) Management- Organising Daily Life

I'm now going to ask you a few questions about your day to day life and how you organise it.

(14)(a) Could you look at the diary I have prepared.....Could you tell me what you did yesterday: morning, afternoon and night?

Was it a typical day or was it unusual in some way?

What about the day before? etc What did you do morning, evening and night?

Was it typical or was it unusual in some way?

(b) Looking at the diary again, what do you think your ordinary day would have looked like before your diagnosis?

(c) Looking at the diary now, how much time do you think you had over the last week just for your self, when you were not working, looking after the house or the children?

Has this changed since your diagnosis?

2) Difficult Circumstances

(15) Now I'm going to ask more about things/ circumstances that are difficult to cope with.

(a) Can you give me any examples of things or circumstances which you would find difficult to deal with?

(b) has anything like this ever happened?

Y N

(if no: Has there ever been an occasion when you've found something or some circumstances difficult to cope with?)

(if so) Can you tell me about it?

(c) How did you handle it?

(d) How did it make you feel?

(e) Did you think of getting any help from anyone or anywhere? Y N

(prompts)	was this from friends	Y	N
	family	Y	N
	another source	Y	N

(f) Did you actually contact anyone? Y N

Who did you contact?

(g) So you thought of contacting, but didn't actually contact them. Can you remember why not?

(h) How about 1).....; 2).....; 3)..... (from the original sheet), did you think about contacting them?

(i) How did it all affect you?

- (j) How often have such situations arisen?
- never
 - once a year or less
 - once every 6 months
 - once every month or 2
 - once a week
- (k) Can you give me any other examples of difficult things/ circumstances you have had to deal with ?

(E) Use of Social Services: Past, Present and Future

(16) I’m now going to ask you some questions about the social services you have used. I’m going to ask you about a wide range of organisations, some are just for people with HIV and some are not.

(a) Could you give me the names of agencies that you know about that provide services for people with HIV infection?

(17) Could you look at this list of organisations (*hand over a list of organisations-with addresses*). I’m going to ask you some questions about them. (*Go through all the questions for one agency before moving to another*).

On my sheet:	(A)have you heard of?		(B) have you ever used?	
SOLAS	Y	N	Y	N
	(if so) how?		what did they do for you?	
Positive Help	Y	N	Y	N

	(if so) how?	what did they do for you?
Riverside	Y N	Y N
	(if so) how?	what did they do for you?
SATA	Y N	Y N
	(if so) how?	what did they do for you?
Body Positive	Y N	Y N
	(if so) how?	what did they do for you?
Milestone	Y N	Y N
	(if so) how?	what did they do for you?
Spittal Street	Y N	Y N
	(if so) how?	what did they do for you?
CAST	Y N	Y N
	(if so) how?	what did they do for you?
GUM clinic	Y N	Y N
	(if so) how?	what did they do for you?
City Hospital	Y N	Y N
	(if so) how?	what did they do for you?
SAFE	Y N	Y N
	(if so) how?	what did they do for you?
SAM	Y N	Y N
	(if so) how?	what did they do for you?

GP	Y	N	Y	N
----	---	---	---	---

if so how?

what did they do for you?

Have you used any other agencies since your diagnosis, including those not just for people living with HIV eg.

Advice Shop/Bridges	Y	N	Y	N
---------------------	---	---	---	---

Housing Advice Centre	Y	N	Y	N
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The Links Project	Y	N	Y	N
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Brenda House	Y	N	Y	N
--------------	---	---	---	---

NEDAC	Y	N	Y	N
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Any informal/ unofficial self-help groups? Y N

Social Work Dept	Y	N	Y	N
1				
2				
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(if so) how?

what did they do for you?

Did you have any contact with the SWD in the past before diagnosis? Y N

Was that useful?

(b) (If relevant) Of the places you've heard of but not used (for example.....).

Did you ever think of using them and then decide not to?

(if so) Could you tell me why?

(c) Which was the first organisation you contacted?

Can you tell me about going there for the first time and the story of how you contacted other organisations?

(probe) Did you find it easy to find out about social services?

(18) I'd like you to look at the list of services on the sheet I gave you again. Could you tell me which social services you have used in the last 6 months? (*I will ask people to tell me and then ask about frequency of use*).

SOLAS	Y	N	daily	weekly	monthly	less
Positive Help	Y	N	daily	weekly	monthly	less
Riverside	Y	N	daily	weekly	monthly	less
Milestone	Y	N	daily	weekly	monthly	less
SATA	Y	N	daily	weekly	monthly	less
NEDAC	Y	N	daily	weekly	monthly	less
Body Positive	Y	N	daily	weekly	monthly	less
CAST	Y	N	daily	weekly	monthly	less
Spittal Street	Y	N	daily	weekly	monthly	less
SAM	Y	N	daily	weekly	monthly	less
SAFE	Y	N	daily	weekly	monthly	less
City Hospital	Y	N	daily	weekly	monthly	less
GP	Y	N	daily	weekly	monthly	less

Any others?:	daily	weekly	monthly	less
	daily	weekly	monthly	less
	daily	weekly	monthly	less

SWD	Y	N	daily	weekly	monthly	less
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(b) I notice that you haven’t mentioned using x,y,z in the past 6 months. Can you tell me why you haven’t used this agency?

- 1) Why not?
- 2)..... Why not?
- 3)..... Why not?

(c) Which of these services are the most important to you?
 Why?

(e) Thinking back over the last 6 months, can you remember being unsure about using any services? Y N

(If so) Can you remember why?

(f) As you know, the Social Work Department has legal duties to do with community care provision and the protection of children. Do you see any other agencies as similar to the SWD?

(20) I'm now going to go give you some flashcards. Could you pick out the ones which best describe the organisations you have used. We can discuss your responses afterwards.

How would you describe.....: (Have several pages of this ready ie so that the information can be recorded for each different organisation).

caring	Y	N		like the police	Y	N
judgmental	Y	N		good at explaining	Y	N
warm	Y	N		child-friendly	Y	N
welcoming	Y	N		women-friendly	Y	N
intrusive	Y	N		open to your ideas	Y	N
ready to listen		Y	N	bossy	Y	N
treat you like a child	Y	N		realistic	Y	N
always watching you	Y	N		flexible	Y	N
easy to get to		Y	N	understand you	Y	N
easy to get involved with		Y	N	careless with information	Y	N
have strings attached	Y	N		comfortable with HIV	Y	N

(21)(a) Could you tell me why you have chosen these words?

(b) Have you ever complained about any services you have received? Y N

(If so) Can you tell me about that?

(22) Are you involved in the running of any organisations whether HIV related or not? (eg any committees) Y N

(if so) Could you tell me about that?

(if not) Why is that?

(G) Impressions of Social Services as a Whole

(24) Looking back on your use of services since your diagnosis:

(a) From your experience, what advice about services would you give to a mother who has just been diagnosed as HIV positive?

(b) And what other general advice would you give her? (*ie not necessarily related to services*)

(c) Would you advise a mother with HIV to go to the SWD? Y N

Why/ Why not?

(d) Do you have an opinion on whether social services as a whole are getting better or worse? Y N

Can you tell me about that?

(25) I'd like to ask you whether you know any mothers with HIV who you know have decided *not* to use any social services? . Y N

(if so) Why do you think they have made this decision?

(b) Do you know any mothers who have used social services in the past but have stopped using them? Y N

(c) Why do you think they have made this decision?

Attempt at snowballing:

In this project I also am interested in talking to mothers with HIV who are not in contact with social services and with mothers who may be in contact with their GP and the City Hospital but are not in contact with the other agencies we've been talking about today.

If you do know any such mothers, I would like to ask you to think about asking them if they would be willing to talk to me? You don't have to tell me now, but could think about it. If anyone was interested then you could give me their name and number (if they consented of course), or they could contact me on this number..... (In other words I would know nothing about them, unless you felt ready to ask them, and they agreed).

Checklist (for own use):

- marital status?

- age?

- age when you left school?
- age when diagnosed?
- ages of children?
- do you think that your diagnosis has affected your children in any way?

Finally I'd like to ask you about this interview. Are there things that you would have liked to have talked about being HIV positive and the services that you've used or not used? (eg things that you think are important but which you haven't had the opportunity of talking about).

Thank you very much for talking to me. It's been really interesting and useful.

As I think you know, I would really like to talk to you again in 3- 4 months time. May I contact you again in 3 or so months time for a second interview? If you sign this form I will know that you have agreed that I can contact you again. Signing it now does not mean that you have to talk to me. Also, if you change your mind, you can say no later.

Finally, it would also help me if in the meantime you noted down the visits you make between now and our next meeting to any social service organisations (or kept appointment cards). I've got a notebook here. It would be very helpful if you could write down in it when you've used different services and what you thought of them. You could give it back to me at the next interview or send it back to me using this SAE.

Appendix 4

This text of the interview has had to be reconstituted by looking at second interview transcripts, all of which had been adapted for use in Nu.dist. Unfortunately the file on which I had saved the master version of this topic guide seems to have corrupted during a period when I did not have access to a computer.

Each second interview was customised to the individual respondent based on analysis of their first interview.

Second Topic Guide for Mothers

Thank you very much for agreeing to be interviewed again.

Just to explain about this research again, I'm doing a PhD at Edinburgh University on HIV-positive mothers, their experience of living with HIV infection, and their use of services. I'm focusing on these issues as I don't think that enough is known about the particular experiences, needs and opinions of HIV positive women. For example, I would like to find out how well you think social services fit into your everyday life, how well they meet your needs.

This interview will be quite similar to the last one but I will also ask you about some of the issues that have been raised by looking at the first interviews.

I'd also like to emphasise confidentiality again. I won't write your real name in my notes. Nothing I write will allow people who don't know you to figure out your identity.

Throughout the interview, please remember that you can stop at any time. If there are any questions that you don't want to answer, then just tell me and we'll move on. Or if you want me to explain why I'm asking a particular question then just ask.

Like last time I have a tape-recorder with me so I can concentrate more on what you are saying rather than taking notes. Do you mind if I use it? If you want me to turn it off at any point during the interview then just tell me.

Would you mind signing this consent form?

Do you have any other questions or concerns before we start?

(Notes for Self)

Date:

Place of Interview:

Organisation through which respondent contacted:

Name to be identified by:

Time taken: Start: Finish:

My comments/ observations after the interview:

Catching up

How have you been since the last interview?

How's your health?

Last time you told me you were has this changed?

How are your children?

Something I didn't ask you in the last interview is whether or not you are religious? ..

(If so, does that help you?).

(Do you go to church?)

(Do you talk to the minister/ priest?)

Income and Housing

Have you had any problems with the DSS since the last interview?

Have you been worried about your benefits?

Are you happy with your housing?

Have you had any transport problems?

Changes in Social Support

Has who you live with changed since the last interview?

Has the list of people important to you changed [*hand over list from previous interview*]

Have you been in contact with all the people on that list?

And in general have things changed since the last interview?

Attitudes Towards Housework

Several of the HIV-positive mothers I have interviewed have told me that they do not want to have a home-help. One of them told me that that would feel like giving up. Do you agree with this view or do you see having a home-help differently?

Have you ever had a home-help?

(If so, would you do it again?)

(If not, why not?)

Do you like using services that come to your home or do you prefer to go out?

Surviving Until 16

Several of the women I have interviewed have told me that one of their main aims has been to survive until their youngest child reaches the age of 16. Do you know what they mean by this?

(If not, why do you think they said that?)

(Is this aim important to you?)

(If so When did you set this aim?)

(Why is the age of 16 important?)

(Do you think it will be difficult for you when your youngest child reaches 16 the age of 16?) ...

(Do you think about your youngest child getting to 16?)

Have you had any help with the children?

(If so How long have you had access to that service?)

Do you have any plans if you are too ill to look after child?

Have you made a will?

(Why's that? Why not?)

One woman told me she was scared of making a will. Do you understand what she meant by that?

Management – Organising Daily Life

Like last time, I'm now going to ask you a few questions about your day to day life and how you organise it.

Could you tell me what you did yesterday: morning, afternoon and night?

Was it a typical day or was it unusual in some way?

What about the day before? etc What did you do morning, evening and night?

Was it a typical day or was it unusual in some way?

How much time do you think you had over the last week just for yourself, when you were not looking after the house or the children?

Difficult Circumstances

Can you give me any examples of things or circumstances which you have found difficult to deal with since the last interview?

(if so) Can you tell me about it?

How did you handle it?

How did it make you feel?

Did you think of getting any help from anyone or anywhere?	Y	N
<i>(prompts)</i> was this from friends	Y	N
family	Y	N
another source	Y	N
(f) Did you actually contact anyone?	Y	N

Who did you contact?

- (j) How often have such situations arisen?
- once
- once every month or 2
- once a week

Can you give me any other examples of difficult things/ circumstances you have had to deal with since the last interview?

Last time you mentioned Has this situation arisen/ has this happened since the last interview?

Use of Social Services Since the last Interview

I'd like you to look at the list of services on this sheet. Could you tell me which social services you have used in the last 6 months? *[ascertain whether the notebook has been filled in].*

SOLAS	Y	N	daily	weekly	monthly	less
Positive Help	Y	N	daily	weekly	monthly	less
Riverside	Y	N	daily	weekly	monthly	less
Milestone	Y	N	daily	weekly	monthly	less
SATA	Y	N	daily	weekly	monthly	less
NEDAC	Y	N	daily	weekly	monthly	less

Body Positive	Y	N	daily	weekly	monthly	less
CAST	Y	N	daily	weekly	monthly	less
Spittal Street	Y	N	daily	weekly	monthly	less
SAM	Y	N	daily	weekly	monthly	less
SAFE	Y	N	daily	weekly	monthly	less
City Hospital	Y	N	daily	weekly	monthly	less
GP	Y	N	daily	weekly	monthly	less
Any others?:		daily	weekly	monthly	less
		daily	weekly	monthly	less
		daily	weekly	monthly	less
SWD	Y	N	daily	weekly	monthly	less

Have you used any unofficial groups in that time?:

(if services used previously are not mentioned) Last time you told me that you had used the following services in the previous six months. Have you used [....] since the last interview?

Chronology of Service Use

In this section I am going to ask you some questions, based on the first interview, about how you came to use services.

Did the way you were told you were HIV-positive put you off using services at all?

(if relevant) When you had [child], did you know you were HIV-positive at that point?

(if so) What was the attitude of doctors to your pregnancy?)

(if relevant) Did that put you off using services for [child]?

When you started to use services, do you think it was easier to go to medical or social organisations?

(if any early service use) How did you get involved with [....]?

When you were diagnosed did anyone tell you where to go for services?

Was this/ would that have been helpful at the time?

(prompt Would you have used the information at that time?)

How was it when you first started to use [....]?

Have you ever felt that you were using services too much?

(If yes) Can you tell me about that?

What did you do?

Trying to Build an Individual Chronology

[discussion of the time-lines I constructed from analysis of the first interviews].

If you don't mind, I'd like you to have a look at this diagram. It represents what you told me in the first interview about when you started to use different services and what was going on in your life at that time. Please tell me where I've got it wrong. If you would like to correct it yourself then please use these pens.

(give the respondent the time to have a look at the time-line and to answer any questions)

The next questions are to try and get a better idea of things that might have affected your service use over the years. *(use the customised list for each respondents)*

For example:

When did you start to tell your friends and family you were HIV-positive?

Was it harder to use services before you told them?

How long were you involved with the support group you told me you used in the 1980s?

And you got into contact with them through [....]?

Do you like the self-help style of services?

(Why/ Why not?)

So you used [.....], did you contact any other services?)

And when did you start to use Solas?

You told me that [another family member] was HIV-positive, did you ever get any information through him/her?

I think you told me you used drugs years ago, have you ever been on a methadone programme or other substitute prescription programme?

Do you think you could have used any services if you were still using any drugs?

And you told me last time that it was about [dates] that you started telling people about your diagnosis? Is that right?

Do you think it was more difficult to use services before your friends knew?

What about using services before your child[ren] knew?

When did you tell him/her/them?

When you contacted services for the first time was it something you had to do or something you sat down and thought about?

Did anyone go with you the first time?

Types of Services Preferred

I am going to ask you about different types of services now and whether or not you have found them important.

Has one to one counselling been important to you? (Why/ Why not?)

Has meeting other women with HIV been important to you? (Why/ Why not?)

Have therapies [such as massage, reiki, aromatherapy etc] been important to you?
(Why/ Why not?)

Have general advice and information services (eg for benefits) been important to you?

(Why/Why not?)

Has respite care been important to you? (Why/ Why not?)

Have services for children been important to you? (Why/ Why not?)

Has medication been important to you? (Why/ Why not?)

Thinking about all of these types of services, which have been the 3 most important to you over the years:

- 1)
- 2)
- 3)

Could you tell me why these types of services have been the most important?

Do you have as much access to these types of services as you'd like?

Who do you prefer to get information from?

What have been the major advantages for you of service use?

Is a lot of the way you use services like self-help?

(If so) what do you mean by this?

Is it important to you to feel that you're helping other people?

Have you had any major problems with services?

(If so, can you tell me about that?)

Thank you

Thank you very much for participating in this project and sparing the time to be interviewed. How did you find the interview? Do you think anything should be changed?

Have you got any questions you would like to ask me about the project?

Appendix 5

Glossary of Social Service Agencies Mentioned

Statutory Services

City of Edinburgh Social Work Department

City of Glasgow Social Work Department

Voluntary Sector Services In Edinburgh

Barnardo's Riverside Project (Lothian) – provides planning, support and advice to children and families affected by HIV and AIDS.

Body Positive (Lothian) – provides advice, support, counselling and information, primarily on a self-help basis.

Brenda House – a rehabilitation unit for women who are drug or alcohol dependent.

Milestone House – a residential convalescence, respite and terminal care facility for people with HIV-illnesses and AIDS.

Positive Help – provides practical help with daily living including transport to hospital, decorating, baby-sitting and children's outings.

Solas – provides a café, a crèche, women's groups, a public information centre, creative arts, complementary therapies and counselling.

The Women and HIV/AIDS Network – promoted awareness of women's HIV-related experiences and needs through training, information, education and conferences and some support to women infected and affected by HIV (now closed).

Voluntary Sector Services In Glasgow

Body Positive (Strathclyde) – provides information, home, hospital and prison visits.
a creche, complementary therapies and counselling.